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Matthew D. Ramsey
Executive Director for the Office of Privacy and Disclosure
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Refer to: S9H: SSA-2019-000087

Dear Executive Director Ramsey,

I write to appeal the following:

(1) I hereby appeal the improper withholding of agency records [1] by the Social Security Administration (SSA) under the Freedom of Information Act (FOIA).

Specifically, I appeal the withholding by SSA of 1,377 page(s) of response documents cited in the SSA response letter (hereafter referred to as the "response letter"; Exhibit A), in fulfillment of the S9H: SSA-2019-000087 FOIA request (hereafter referred to as the "FOIA request"), addressed to me from Ms Mary Ann Zimmerman, and dated July 26, 2019 and received by me via electronic transmittal on July 27, 2019.

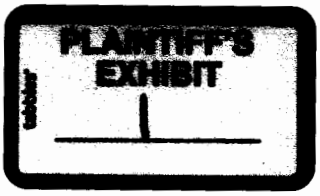
I also appeal the withholding by SSA of any further relevant documents responsive to the FOIA request which SSA may not have included within the 1,377 page(s) of response documents cited in the response letter.

These appeals are made 28 days since the date of the response letter and 27 days since my receipt of the response letter. These appeals are therefore in compliance with the response letter stipulation of transmittal "*within 90 days of the date of our response to your initial request*".

(2) I hereby appeal the fee that SSA assessed for fulfilling the FOIA request and I demand its refund.

Specifically, I appeal the $2,908.00 fee to fulfill the S9H: SSA-2019-000087 FOIA request per the SSA FOIA fee letter to me from Ms Monica Chyn, and dated May 29, 2019 (hereafter referred to as the "fee letter"; Exhibit B) and received by me via electronic transmittal on May 30, 2019.

[1] 5 U.S.C. § 552 (a)(4)(B); Kissinger v. Reporters Committee, 445 U.S. 136 (1980)



I also appeal any right that SSA may assert in the future to assess any further fee to be applicable to fulfilling this FOIA request.

These appeals are made 86 days since the date of the fee letter and 85 days since my receipt of the fee letter. These appeals are therefore in compliance with the fee letter stipulation of transmittal "*within 90 days of the date of our response to your initial request*".

1. Background:

a. On October 5, 2018, I submitted a FOIA request via the FOIA online website[2] for release of SSA documents under the FOIA. The specific language of the FOIA request, as submitted, was:

"*I seek all documents, regardless of age, pertaining to SSA assessment, evaluation, and decisions regarding inclusion or exclusion of a proposed listing for impairments due to migraine and other headache disorders in the SSA Listing of Impairments (Blue Book). These documents should relate to, but not be limited to, the 2013 to 2016 process of SSA rules-making, ANPRM, NPRM and final rules-making for revision of Medical Criteria for Evaluating Neurological Disorders listings (11.00 Neurological – Adult). These documents should include, but be not limited to, all relevant correspondence, emails, memoranda, drafts, cost-benefit analyses, public comments, and related guidance documents, including those documents from and between all relevant SSA offices (i.e. Office of Regulations and Reports Clearance, Office of Disability Policy, Office of General Counsel, Offices of the Chief Actuary and Budget, etc.), as well as those document from and between SSA offices and offices of other Federal Government agencies. I also seek all documents (i.e. from SSA Office of Disability Policy or other SSA offices), regardless of age, pertaining to, and/or informing, guidance as to how Listings of Impairments (e.g 11.02 Epilepsy) are to be appropriately utilized and interpreted (i.e. by SSA adjudicators and administrative law judges) in order to assess and determine medical equivalency with impairments attributed to, or caused by, migraine or other headache disorders, such as cluster headache.*"

b. On October 5, 2018, I received email confirmation from SSA that the FOIA request was successfully submitted (Exhibit C).

c. On May 30, 2019, I received the fee letter dated May 29, 2019 via email.

The letter informed me that SSA had decided that my "*request is for non-program related purposes and therefore, the agency should charge the full costs it incurs when providing you this information*". SSA offered no further explanation or justification as to why SSA declared the request to be "*for non-program related purposes*".

[2] https://foiaonline.gov/foiaonline/action/public/request

The fee letter further informed me that I would need to provide a fee of $2,908.00 within 10 days in order to proceed with SSA fulfillment of the FOIA request.

d. On June 5, 2019, I submitted to SSA via email a completed credit card charge form to authorize payment of the $2,908.00 fee to proceed with fulfillment of the FOIA request.

e. On June 6, 2019, I received from SSA via email an acknowledgment of payment of $2,908.00 fee to proceed with fulfillment of the FOIA request (Exhibit D).

f. On July 15, 2019, I sent an email to FOIA.Public.Liaison@ssa.gov requesting "*an estimate as to when I may expect to receive the documents*" in light of "*Guidance from the SSA FOIA site is that SSA FOIA requests are typically completed within 20 federal workdays of initiating the process*". I received no reply to this email.

g. On July 27, 2019, I received the response letter dated July 26, 2019 via email.

h. On August 12, 2019, my credit card company received and approved a request from SSA for a charge of $2,908.00.

2. **Basis for appeal of the SSA withholding of 1,377 page(s) of response documents and any withholding of any further documents relevant to the FOIA request:**

a. It is uncontested that "*The Commissioner of Social Security shall have full power and authority to make rules and regulations and to establish procedures...*" [3].

b. It is also uncontested that significant deference is generally accorded to the SSA Commissioner in rule-making and in the interpretation and the enforcement of resulting rules and regulations [4].

c. Judicial deference does not, however, apply to the withholdings claimed by SSA in the response letter since acts of withholding the documents are in violation of the Administrative Procedure Act of 1946, and as amended by FOIA, as "*arbitrary, capricious, or otherwise not in accordance with law*" [5].

i. SSA, arbitrarily and capriciously, delayed their response to the FOIA request, without reason or justification.

The Freedom of Information Act states that:

"*Each agency, upon any request for records made under paragraph (1), (2), or (3) of this subsection, shall... (i) determine within 20 days*

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[3] 42 U.S.C. § 405(a)
[4] Chevron U.S.A. Inc. v. Natural Resources Defense Council, 467 U.S. 837 (1984)
[5] 5 U.S.C. § 706(2); Sullivan v. Zebley, 493 U.S. 521, 530 (1990)

(excepting Saturdays, Sundays, and legal public holidays) after the receipt of any such request whether to comply with such request and shall immediately notify the person making such request of such determination and the reasons therefor, and of the right of such person to appeal to the head of the agency any adverse determination..." [6]

Subsequent to my receipt, on October 6, 2018, of SSA confirmation that the FOIA request had been successfully submitted, I received no further contact from SSA until I received the fee letter on May 30, 2019, 237 days following submission of the FOIA request.

I received the response letter 294 days following submission of the FOIA request, 61 days following my receipt of the fee letter, and 56 days following my receipt of SSA acknowledgement of receipt of my fee payment authorization.

The multiple, unjustified, and consistently prolonged delays in the responses by SSA to the FOIA request are in violation of the FOIA Statute.

ii. The response letter, arbitrarily and capriciously, cited an abridged version of the FOIA request.

The following language of the FOIA request was deleted in the response letter, without reason or justification:

"*These documents should include, but be not limited to, all relevant correspondence, emails, memoranda, drafts, cost-benefit analyses, public comments, and related guidance documents, including those documents from and between all relevant SSA offices (i.e. Office of Regulations and Reports Clearance, Office of Disability Policy, Office of General Counsel, Offices of the Chief Actuary and Budget, etc.), as well as those document from and between SSA offices and offices of other Federal Government agencies.*"

SSA has not indicated whether response documents exist that would be prompted by this deleted request language, and that are not included in the indicated 1,377 withheld page(s) of response documents cited in the response letter.

"*What the agency must show beyond material doubt is that it has conducted a search reasonably calculated to uncover all relevant documents.*" [7]

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[6] https://www.justice.gov/oip/blog/foia-update-freedom-information-act-5-usc-sect-552-amended-public-law-no-104-231-110-stat

[7] Weisberg v. U.S. Dept. of Justice, 705 F.2d 1344 (D.C. Cir. 1983)

In light of this deleted FOIA request language, there is material doubt that SSA ever conducted an adequate and reasonable search for all response documents relevant to the complete FOIA request (see below, subsection 2.c.iv.4).

If additional relevant response documents do exist, SSA must also provide these documents to fulfill the complete FOIA request.

iii. Documents were attached to the response letter that are irrelevant and immaterial to the FOIA request, but SSA, arbitrarily and capriciously, claimed that they comprised a "*partial grant*" of the FOIA request. [8]

For example, SSA provided no explanation, reason, justification, or relevance to the FOIA request, for those documents attached to the response letter that pertain solely to Huntington Disease (Exhibit E), or to the Fall Unified Agenda and Reg Plan (Exhibit F).

iv. The response letter, arbitrarily, capriciously, and unlawfully invoked FOIA Exemptions 5 and/or 6 to withhold documents, without reason or justification [9] and is an unconstitutional overreach of the "deliberative process exemption".

1. The Social Security Act has been designated by Congress and interpreted by the courts as "remedial" in nature [10]. In other words, the Act should be interpreted broadly to achieve its intended purpose in providing necessary benefits to individuals who are unable to work due to disability. In interpreting a remedial statute, exceptions to disclosure of necessary information should be narrowly construed and limited in scope. Individuals seeking to enforce the Act's provisions should be given the greatest access possible to the Agency's decision-making processes. As such, the exemptions to disclosure of the requested information cited by the Agency should be narrowly construed, and should not shield the disclosure of the documents requested here. SSA provides no explanation for why basic research and data gathering by claimants and their representatives to enable them to file valid claims should be restricted by invocation of the "deliberative process exemption", or why such documents would be lawfully subject to Exemption 5 privileges at all.

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[8] Exhibit E; "Memo – 2017 Fall Unified Agenda and Reg Plan (8-9-16)" Exhibit F

[9] https://www.justice.gov/oip/foia-guide-2004-edition-exemption-5

[10] Schmiedigen v. Celebrezze, 245 F. Supp. 825, 827 (D.C. 1965); Marcus v. Califano, 615 F.2d 23 (2d Cir. 1979); Smith v. Chater, 99 F.3d 780 (6th Cir. 1996)

2. In the context of a remedial statute, invocation of the "deliberative process exemption," as applied to the documents sought here, would be unconstitutional. Individuals doing business with and/or seeking statutory benefits that the Agency administers have a due process interest in obtaining full and complete information concerning the Agency's decision-making process.

3. Without a lawful basis for SSA invocation of the "deliberative process exemption", claimants are entitled to the full disclosure by SSA of all relevant guidance documents, as well as the documentation of the background and deliberative considerations that led to them, that are possessed by SSA and that could impact the successful filing and evaluation of their disability claims.

   Such relevant documents would include, but not be limited to, compilations of medical research, medical opinion letters, data compilations, statistical studies, briefing papers interpreting medical information, drafts of potential rules and rulemaking announcements, preliminary reviews and analyses, etc..

4. However, since SSA decision-making and its documentation is opaque to public view, it is impossible for claimants to specify all documents which plausibly exist and would therefore be subject to FOIA disclosure, though some obvious examples of withheld documents include:

   a. The response letter withheld SSA guidance documents relevant to the evaluation of migraine and headache disorders impairments that SSA currently provides to DDS adjudicators (see below, subsection 2.f.vi, final rule-making [11], and Exhibit K).

   b. The response letter withheld documents that are material to the FOIA request but that are already in the public domain.

      For example, the FOIA request specified disclosure of all relevant public comments, yet SSA notably withheld documents for such comments that were submitted during the (2/25/14) – (4/28/14) NPRM public comment period and are available on-line [12].

   c. The response letter withheld documents that are material to the FOIA request that are greater than 25 years old and that cannot be lawfully withheld under FOIA Exemption 5.

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[11] https://www.govinfo.gov/content/pkg/FR-2016-07-01/pdf/2016-15306.pdf
[12] NPRM (79 FR 24634). https://www.regulations.gov/document?D=SSA-2006-0140-0059

The FOIA Statute states:

"*...the deliberative process privilege shall not apply to records created 25 years or more before the date on which the records were requested.*" [13]

Undoubtedly, SSA documents exist from prior to October 5, 1993 that are relevant to the evaluation of impairments due to migraine and headache disorders, and that are material to the FOIA request.

i. SSA Q&A 09-028 [14], and any documents related to its consideration, drafting and approval, are response documents that have been unlawfully withheld.

   The SSA guidance document for migraine claimants, SSA Q&A 09-036 (Exhibit G) [15], from December 15, 2009, makes reference to SSA Q&A 09-028 (*"revises archived Q&A 09-028")* and also makes reference to relevant SSA guidance documents from the early 1990's (*"Previous guidance from the Office of Disability from the early 1990's stated that...*").

ii. Migraine is the 2nd leading cause of US disability [16], and it is simply implausible that SSA had not considered the impact of migraine disability until after October 5, 1993.

v. As cited above, SSA failed its statutory obligations to respond to the FOIA request and acted in bad faith in fulfilling the request.

   The SSA response letter was untimely, deleted explicit request language (which it may not have responded to at all), disclosed irrelevant documents, and unlawfully invoked FOIA Exemption 5 and/or FOIA Exemption 6 to withhold response documents material to the FOIA request.

   By these collective, arbitrary, capricious, and unlawful actions and

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[13] https://www.foia.gov/foia-statute.html
[14] Merritt v. Comm'r of Soc. Sec., 15-CV-6633-CJS (W.D.N.Y. Oct. 26, 2016); McShane v. Berryhill, CIVIL NO. 15-5137 (W.D. Ark. Feb. 1, 2017)
[15] SSA Q & A 09-036 (12/15/2009) (Exhibit G)
[16] https://vizhub.healthdata.org/gbd-compare/

inactions, SSA has undermined the validity, legitimacy, and credible basis of any claims SSA may have asserted, or may further assert, to withhold any of the 1,377 page(s) of response documents cited in the response letter, or any other response documents that would be prompted by the valid request language that was omitted in the response letter.

Specifically, since SSA demonstrably and multiply invoked Exemption 5 unlawfully, I do not assume, and cannot accept, that any SSA invocations of FOIA Exemptions 5 or 6 were made in good faith.

vi. Accordingly, and without conceding that any exemption claimed by SSA would be lawful, if SSA continues to assert a right to withhold any documents under the "deliberative process exemption" or any other invoked exemption or privilege, I expect that SSA will fully justify their denial of each and every page of documents.

Specifically, I expect SSA to list in detail every document withheld (including title, description, date, who created it, and who it was sent to) and explain in detail the specific reason that SSA is withholding each document. Where an exemption is still claimed, SSA must nonetheless consider whether parts of documents could be produced in redacted form, and then provide these documents.

"*FOIA's strong presumption in favor of disclosure means that an agency that invokes one of the statutory exemptions to justify the withholding of any requested documents or portions of documents bears the burden of demonstrating that the exemption properly applies to the documents.*" [17]

d. There is further probable cause to conclude that SSA's act of withholding the response documents in the response letter was "*otherwise not in accordance with law*" and "*in excess of statutory jurisdiction, authority, or limitations, or short of statutory right.*"[18]

e. By withholding of response documents in the response letter, SSA unlawfully invoked the "deliberative process exemption" to shield from public exposure SSA violations of law.

i. The US District Court for the Southern District of New York has held that:

"*it is utterly implausible to suppose that Congress intended FOIA Exemption 5 to shield government documents when they were created for*

[17] Lahr v. National Transportation Safety Board, 569 F.3d 964 (9th Cir. 2009)
[18] 5 U.S.C. § 706(2)

the purpose of furthering a crime or a fraud." [19]

ii. As elucidated below, SSA appears to have invoked FOIA Exemption 5 in the response letter not exclusively with lawful intent to protect the SSA deliberative processes from "fear of public scrutiny", but rather with malign intent to shield from necessary public scrutiny some SSA deliberations and decisions that were in furtherance of SSA violations of law, as they pertain to the 2016 final rule-making for revision of the Medical Criteria for Evaluating Neurological Disorders (hereafter referred to as the "final rule-making") [20] and the process of Sequential Evaluation.

f. Specifically, the final rule-making was, itself, in violation of the Administrative Procedure Act of 1946 in that it was "*arbitrary, capricious, or otherwise not in accordance with law*".

i. The final rule-making, arbitrarily and capriciously, excluded the addition of a listing to the Blue Book Listings of Impairments for migraine and other headache disorders, without reason or justification. SSA has provided no explanation for this decision either in the final rule-making or subsequently.

At the time of the final rule-making, SSA was in possession of more than sufficient information upon which to strongly justify the addition of a headache disorders listing to the Blue Book.

On March 15, 2013, approximately eleven months prior to the Notice of Proposed Rulemaking (NPRM) for revision of the Neurological Listings (February 25, 2014), the Alliance of Headache Disorders Advocacy (AHDA) [21], a 501(c)(6) not-for-profit advocacy organization, submitted a model draft headache disorders Blue Book listing to SSA, with extensive, detailed, and explanatory prefatory matter (Exhibit H).

Subsequently, on April 27, 2014, during the public comment period following the NPRM, AHDA submitted to SSA an appeal letter that contained further data supportive to this request (Exhibit I).

Moreover, during this NPRM comment period, SSA also received more than 842 public comments supportive of the addition of a headache disorders listing, comprising more than 30% of the total (2,780) public comments received during the comment period of the NPRM.

At the time of the AHDA submissions to SSA (i.e. 2013-2014), the

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[19] Nat'l Immigration Project of Nat'l Lawyers Guild v. DHS, No. 11-3235, 2014 WL 6850977 (S.D.N.Y. Dec. 3, 2014) (Rakoff, J.)

[20] https://www.govinfo.gov/content/pkg/FR-2016-07-01/pdf/2016-15306.pdf

[21] https://allianceforheadacheadvocacy.org/

AHDA was comprised of all of the major US regional and national not-for-profit patient and professional organizations in existence at that time that represented the advocacy interests of American migraine and headache disorders patients. These organizations included:

Alliance for Patient Access, American Academy of Neurology, American Headache Society, Clusterbusters, Headache Cooperative of New England, Headache Cooperative of the Pacific, Migraine Research Foundation, Miles for Migraine Races, National Headache Foundation, National Migraine Association / MAGNUM, Ohio Headache Association, and the PFO Research Foundation.

ii. The decision to not add a headache disorders listing in the final rule-making, arbitrarily and capriciously, violated federal regulations that explicitly direct SSA to ensure that the listings reflect the "*more commonly occurring impairments*":

1. "*The impairments listed in Appendix 1 provide a means to efficiently and equitably evaluate the more common impairments.*"[22]

2. "*The Listing criteria are intended to identify the more commonly occurring impairments...*" [23]

3. "*The Listing includes medical conditions frequently diagnosed for people who file for disability benefits.*" [24]

Moreover, SSA certainly knew at the time of the final rule-making that migraine is indisputably one of the "*more commonly occurring impairments*" that lead to disability in the United States.

4. Among other pertinent data, the prefatory matter in the March 15, 2013 AHDA submission to SSA (Exhibit H) informed SSA of published data from the 2010 Global Burden of Disease / World Health Organization study that migraine "*is estimated to be the 7th ranking single cause of all disease-associated disability (YLDs) worldwide*".

5. Among other pertinent data, the April 27, 2014 AHDA submission to SSA (Exhibit I) informed SSA of published data to the effect that "*migraine alone accounts for more than half of global neurological disability (YLDs).*"

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[22] 42 Fed. Reg. 14706 (1977)
[23] 44 Fed. Reg. 18175 (1979)
[24] 50 Fed. Reg. 50069 (1985)

6. Updated 2017 data from this same Global Burden of Disease / World Health Organization study show that migraine was the 2nd leading cause of US disability (YLDs), accounting for 5.12% of total US disability, and affecting more than 68.5 million (22.5%) Americans [25].

7. Moreover, of the ten leading causes of US disability (YLDs), both in 2013 (at the time of final rule-making) and in 2017, migraine and opioid use disorders were the only two disease categories that remain without an applicable listing in the Blue Book [26].

iii. The final rule-making, arbitrarily and capriciously, ignored or dismissed significant disparate impacts on Americans disabled by migraine for which probable cause exists that the absence of a Blue Book listing for headache disorders, or inadequate migraine-specific guidance, play a significant role, either in whole or in part, in the development and persistence of these disparities.

1. While migraine accounted for 5.65% of total US disability in 2000, only 0.3% of all SSDI claimants based their claims principally on migraine impairments during the period from 1997 to 2004 [27].

2. Initial allowance rates for these few migraine SSDI claimants were markedly lower (23%) than the initial allowance rates for SSDI claimants overall (46%).

3. Of 170 disease categories reported and analyzed by SSA, migraine SSDI claimants are in the bottom 13th percentile for disease categories ranked by initial allowance rate.

4. The analyses noted above were derived from data that SSA published in 2013. Therefore SSA knew, or should have known, at the time of the final rule-making in 2016, that participation rates and initial allowance rates for migraine SSDI claimants were anomalously low.

5. Further, an SSA report of combined SSDI/SSI claimants in 2009, and published by SSA in 2018, found that initial allowance rates for migraine SSDI/SSI claimants were markedly lower (17%) than

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[25] https://vizhub.healthdata.org/gbd-compare/

[26] https://vizhub.healthdata.org/gbd-compare/
Global Burden of Disease study rank of diseases as percent of total US YLDs in 2017:
1 – Low back pain, 2 – Migraine, 3 – Diabetes type 2, 4 – COPD, 5 – Anxiety disorders, 6 – Major depression, 7 – Neck pain, 8 – Other musculoskeletal disorders, 9 – Opioid use disorders, 10 – Age-related hearing loss

[27] https://www.ssa.gov/policy/docs/ssb/v73n2/v73n2p39.html#tableA1
https://vizhub.healthdata.org/gbd-compare/

the initial allowance rates for SSDI/SSI claimants overall (38%).[28]

6. The absence of a headache disorders Blue Book listing can be reasonably assumed to play a significant role in accounting for these major disparities in claimant participation rates and initial allowance rates. That is, the absence of a headache disorders listing creates a significant additional and undue regulatory step, burden, and barrier to claimants and their claimant representatives, thereby discouraging migraine claimants from filing legitimate and valid claims.

iv. The final rule-making, arbitrarily and capriciously, included no applicable new guidance from SSA regarding the Sequential Evaluation process for migraine claimants, despite the fact that SSA explicitly stated in the final rule-making that this guidance is necessary:

"*We realize it is appropriate to provide impairment-specific guidance on how we evaluate migraines and other chronic headache disorders.*"

Furthermore, on January 29, 2019, I spoke for an hour in teleconference with Associate Commissioner Gina Clemons, SSA Office of Disability Policy, about the need for SSA impairment-specific guidance for migraine and headache disorders claimants, such as a Social Security Ruling (SSR). Subsequently, on February 9, 2019 and then on March 13, 2019, I emailed Associate Commissioner Clemons further documents relevant to informing SSA in development of such guidance. These documents included (1) a migraine disability fact sheet, (2) a document on discrimination of women with migraine in the workplace produced by the Aimed Alliance, and (3) a briefing paper on Disability and Migraine Disease produced by the Headache and Migraine Policy Forum.

It is now over three years since the final rule-making (July 1, 2016) and almost seven months since my teleconference conversation with Associate Commissioner Clemons (January 29, 2019), and there is no indication that SSA is any closer to providing claimants with the "impairment-specific guidance on how we evaluate migraines and other chronic headache disorders" that SSA has stated is necessary and appropriate. This continued absence of guidance underscores the urgency of full disclosure by SSA of the response documents under the FOIA request.

v. The final rule-making, arbitrarily and capriciously, rendered obsolete all prior guidance by SSA regarding how migraine and headache disorders SSDI/SSI claimants should appropriately apply the existing Blue Book Listings in the Sequential Evaluation process.

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[28] https://www.ssa.gov/policy/docs/workingpapers/wp113.html

Prior to the final rule-making, SSA provided limited guidance to potential migraine SSDI claimants in three documents (Exhibits G, J, K) [29].

These documents stated that non-convulsive epilepsy [11.03] was "the most analogous listing" to migraine in the Blue Book. However, in the final rule-making, SSA deleted 11.03, thereby eliminating any relevant reference to a listing for the purposes of these guidance documents.

The final rule-making included a new listing: 11.02 (B or D) Dyscognitive seizures.[30] On March 29, 2017, SSA reportedly [31] revised POMS DI 24505.015(B)(7)(b) (Exhibit J) to designate 11.02 to replace 11.03 as "the most analogous listing" for consideration of migraine claimants, but this revised document is not available on the SSA website. SSA Q & A 09-036 (12/15/2009) (Exhibit G) is also not available on the SSA website. It is therefore unclear what SSA guidance, if any, is currently active for migraine claimants. In the absence of explicit guidance it cannot be assumed that 11.02 replaces 11.03.

Furthermore, significant differences exist for the medical criteria for frequency of seizure events between 11.03 ("*occurring more frequently than once weekly in spite of at least 3 months of prescribed treatment*") and 11.02 ("*occurring at least once every 2 weeks for at least 3 consecutive months*"), and neither of these medical criteria are at all applicable to the relevant frequency, severity, or response to therapies of individuals experiencing disabling migraine attacks.

The Supreme Court has articulated stringent requirements for the valid match of a claimant's impairments to a specific listing:

"*For a claimant to show that his impairment matches a listing, it must meet all of the specified medical criteria. An impairment that manifests only some of those criteria, no matter how severely, does not qualify.*" [32]

In light of the Supreme Court's unambiguous language, it cannot be inferred how any current or past listing or any SSA guidance document might be appropriately applied by migraine claimants to the evaluation of their impairments.

vi. The previously available, but not, revised, rescinded or superseded, SSA guidance documents noted above, arbitrarily and capriciously, offer

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[29] SSA Q & A 09-036 (12/15/2009) (Exhibit G);
POMS DI 24505.015(B)(7)(b) (05/13/2016, reportedly revised 3/29/2017) (Exhibit J);
Letter - SSA Acting Commissioner Carolyn W. Colvin to Senate Finance Committee Chairman Max Baucus (2/6/14) (Exhibit K).
[30] https://www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm#11_02
[31] Despinis v. Comm'r Soc. Sec. Admin., No. 2:16-cv-01373-HZ (D. Or. May. 10, 2017)
[32] Sullivan v. Zebley, 493 U.S. 521, 530 (1990)

contradictory, confusing and outright misleading guidance that impede the ability for migraine claimants to make valid claims.

1. In the guidance document, Exhibit G, SSA included two directly contradictory and mutually unresolvable statements:

    a. "*A diagnosis of migraine headaches requires a detailed description from a physician of a typical headache event...*"

    b. "*Nor do we require a professional observation or third-party description of a migraine headache event...*".

2. In the guidance document, Exhibit G, SSA states that:

    "*...Social Security continues to recognize that migraine headaches will rarely prevent a person from working for a continuous 12 months but that there are exceptions.*"

    This statement misleads adjudicators, claimants, and claimant representatives regarding the prevalence of disabling migraine. For example, the diagnostic criteria for chronic migraine includes 15 or more days with headache per month for at least three months. [33] Chronic migraine is associated with severe disability [34], and may currently effect nearly 1 million Americans with a duration of one year or more.[35]

    Furthermore, the guidance statement suggests misleadingly that migraine related impairments must prevent a person from working for a continuous 12 months. In fact, to "*establish disability under the Social Security Act, it is not necessary for a claimant to show that an impairment "has lasted" for 12 consecutive months... Rather, the claimant also can establish disability by showing the impairment "can be expected to last" that long.*" [36]

3. In the guidance document, Exhibit J, SSA provided a case example of a claimant with disabling migraine that was allowed SSDI benefits, and stated therein that "*...due to all of her* [migraine] *symptoms, she has difficulty performing her ADLs* [Activities of Daily Living]." [37]

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[33] https://ichd-3.org/1-migraine/1-3-chronic-migraine/
[34] Blumenfeld, AM. et al. *Cephalalgia*. 2011;31:301-315; Selekler, HM et al. *J Head Pain* 2015;16:96.
[35] Serrano, D. et. al. *J Headache Pain* 2017;18:101
[36] Edwards v. Colvin, Case No. 3:14-cv-05338-KLS (W.D. Wash. Dec. 15, 2014); 42 U.S.C. § 423(d)(1)(A)
[37] The basic "Activities of Daily Living (ADLs)" include: bathing, grooming, dressing, transferring, toileting, eating https://en.wikipedia.org/wiki/Activities_of_daily_living

This statement misleads claimants and claimant representatives regarding the types of impairments to expect in evaluating disabling migraine. While migraine can often lead to disability, there is no published evidence that the impairments that characteristically arise from migraine lead to inability to perform the basic ADLs.[38]

4. In the guidance document, Exhibit G, SSA stated that it considers a physician's reporting of a migraine claimant's symptoms to be clinical signs during Sequential Evaluation Step 2:

"*...we consider the foregoing findings reported by a physician to be "signs" that establish the existence of migraine headaches as an MDI...*".

This SSA guidance elides the distinction between the terms "symptom" and "sign" found in all medical dictionary definitions, as well as universally accepted in clinical usage and practice, such that these terms lose their meanings altogether.

a. "*Medical definition of **symptom**: subjective evidence of disease or physical disturbance observed by the patient.*"[39]

b. "*Medical definition of **sign** (2): an objective evidence of disease especially as observed and interpreted by the physician rather than by the patient or lay observer.*"

SSA's assertion that a "symptom" is a "sign" is no more valid than the arbitrary assertion that the number pi (π) exactly equals 3.2.[40]

The confusing Exhibit G guidance vis-à-vis symptoms versus signs for assessments in Sequential Evaluation Step 2 is also in contradiction to the discrete treatment of these terms asserted in the Exhibit J guidance for Sequential Evaluation Step 3:

"*When substituting a finding or symptom from a listing, the adjudicator may only substitute symptoms for other symptoms and findings for other findings. Never substitute a symptom for a finding.*"

Finally, the confusing definition of the term "sign" offered in Exhibit G guidance is readily challengeable by Administrative Law

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[38] Gil-Gouveia R, et al. *Cephalalgia* 2015; 36:422-430.
[39] https://www.merriam-webster.com/
[40] https://en.wikipedia.org/wiki/Indiana_Pi_Bill

Judges in appeals of SSDI claims [41] on the basis of the strict levels of evidence that are acceptable to establish medically determinable impairments:

"*The impairment must be established by objective medical evidence (signs, laboratory findings, or both) from an acceptable medical source, not on an individual's statement of symptoms.*" [42]

vii. SSA has, in fact, developed and implemented specific relevant guidance on how best to evaluate migraine impairments in Sequential Evaluation. However, SSA has withheld this crucial guidance from migraine claimants and their representatives, arbitrarily and capriciously, and without reason, justification, or fairness.

1. In Exhibit K, SSA Acting Commissioner Carolyn W. Colvin stated in 2014 that:

   "*Our adjudicators have received specific training and policy guidance on how to evaluate migraine and cluster headaches*".

2. In the 2016 final rule-making, SSA affirmed the existence of this "specific training and policy guidance":

   "*We will address these concerns in training to ensure all adjudicators know how to establish migraine and other chronic headache disorders as medically determinable impairments (MDIs).*"

3. The withholding of this existing "specific training and policy guidance" from migraine claimants is unlawful and in violation of the FOIA Statute:

   "*Each agency, in accordance with published rules, shall make available for public inspection in an electronic format... those statements of policy and interpretations which have been adopted by the agency and are not published in the Federal Register.*" [43]

4. The withholding of this existing "specific training and policy guidance" from migraine claimants is an unlawful invocation of FOIA Exemption 5 which does not protect 'post-decisional documents' or 'secret law' from FOIA disclosure:

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[41] McCormick v. Secretary of Health Human Serv, 861 F.2d 998 (6th Cir. 1988); Frustaglia v. Secretary of Health Human, 829 F.2d 192 (1st Cir. 1987)
[42] https://secure.ssa.gov/poms.nsf/lnx/0425205005; 45 FR 55586; 45 FR 55623; 82 FR 5848
[43] https://www.foia.gov/foia-statute.html

> "*Exemption 5 does not protect final statements of policy or final actions of agencies, which have the force of law or* ***which explain actions the agency has already taken; nor does it protect communications that promulgate or implement an established policy of an agency***." [44] (emphasis added)
>
> "*...the public is vitally concerned with the reasons which did supply the basis for an agency policy actually adopted.*" [45]
>
> "*...an agency will not be permitted to develop a body of "secret law," used by it in the discharge of its regulatory duties and in its dealings with the public, but hidden behind a veil of privilege because it is not designated as "formal," "binding," or "final."*" [46]

viii. In consequence of the SSA actions and inactions noted above, migraine claimants and their representatives have been without clear and certain guidance for acceptable procedures for evaluating migraine disability in Sequential Evaluation for the more than three years that have elapsed since the final rule-making.

This prolonged uncertainty exists despite the acknowledgment by SSA in the final rule-making that SSA needs to provide impairment-specific guidance for headache disorders claimants, as well as the acknowledgment by SSA that it has developed such specific guidance that is provided to SSA adjudicators, but that has been withheld from claimants.

It is impossible to avoid the conclusion that SSA is deliberately, unjustly, and without cause or reason, denying claimants access to the crucial guidance that is necessary to enable them to file their valid claims.

This unreasonable, unexplained, and prolonged withholding of existing guidance to migraine claimants has served, and continues to serve, to discourage such claimants and their claimant representatives from filing legitimate and valid claims.

g. The final rule-making is not eligible for judicial deference to the SSA Commissioner since the final rule-making violates clear and unambiguous statutes of Congress. That is, SSA actions in the final rule-making were "*in excess of statutory jurisdiction, authority, or limitations, or short of statutory right*".[47]

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[44] Brinton v. Department of State, 636 F.2d 600 (D.C. Cir. 1980)
[45] NLRB v. Sears, Roebuck & Co., 421 U.S. 132, 151 (1975).
[46] Coastal States Gas Corp. v. Dept. of Energy, 617 F.2d 854 (D.C. Cir. 1980)
[47] 5 U.S.C. § 706(2)

i. The Rehabilitation Act of 1973, Section 504, prohibits Executive agencies from discriminating on the basis of disability:

"*No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.*" [48]

ii. Step 2 of Sequential Evaluation unlawfully discriminates against migraine claimants on the basis of their disabilities.

As previously noted, by SSA regulation, no disease or disorder that is only manifest by symptoms, and for which no clinically acceptable signs or laboratory findings exist, can be established as a medically determinable impairment. [49]

Migraine currently lacks any clinically acceptable pathognomonic diagnostic signs or laboratory findings, and therefore migraine claimants may be excluded from further consideration of their SSDI/SSI claims based on this discriminatory regulation and policy.

For example, normal head computed tomography (CT) or brain magnetic resonance imaging (MRI) studies has been improperly cited by ALJs in multiple cases as evidence against the presence of an MDI for migraine claimants [50]. However, there are no accepted findings based on these imaging methods for the diagnosis of migraine in current clinical practice:

"*Doctors use MRIs to rule out other possible causes of headache— such as a tumor—meaning that an unremarkable MRI is completely consistent with a migraine diagnosis.*" [51]

Further, it is not the case that a disease that is currently only manifest by symptoms (i.e. an "invisible" disease), may never have medically accepted clinical diagnostic signs and laboratory findings discovered and thereby become "visible". For example, diseases for which insufficient investigative research has been performed may not yet have diagnostic laboratory findings or "biomarkers" discovered and validated in clinical diagnosis.

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[48] 29 U.S.C. § 794

[49] 45 FR 55586; 45 FR 55623; 82 FR 5848

[50] David G. v. Berryhill, Case No. 17-cv-3671 (HB) (D. Minn. Sep. 24, 2018); Martise v. Astrue, 641 F.3d 909 (8th Cir. 2011); Teague v. Astrue, 638 F.3d 611 (8th Cir. 2011)

[51] Moon v. Colvin, 763 F.3d 718 (7th Cir. 2014); Loder, E. *Headache* 2013;53:1651-1659.

This may indeed be the situation for migraine. Among diseases that contribute the most to US disease burden, as analyzed by the National Institutes of Health (NIH), migraine research is by far the least funded by NIH research programs.[52]

There is no legitimate basis for SSA to deliberately discriminate against disabling diseases that are manifest only by symptoms, and no signs or laboratory findings.

iii. Step 3 of Sequential Evaluation unlawfully discriminates against migraine claimants on the basis of their disabilities.

As noted above, lack of a migraine and headache disorders listing is associated with significant disparate impacts in terms of the participation rate for potential migraine claimants to make SSDI claims, as well as in the expectations for initial allowance rates by those considering and actually making migraine SSDI claims.

iv. The SSA process to update the listings unlawfully discriminates against migraine claimants on the basis of their disabilities.

As noted above, SSA has withheld existing guidance from migraine claimants regarding the disability evaluation process, without reason or justification. SSA has also refused to add a headache disorders listing to the Blue Book in violation of multiple regulations that intend the listings to reflect the "*more commonly occurring impairments*".

As noted above, these SSA practices and policies are directly associated with adverse, disparate, and anomalously low participation rates and initial allowance rates for SSDI migraine claimants.

The bases for these discriminatory SSA practices and policies are not known; SSA opinions, recommendations, pre-decisional discussion, and evaluative remarks that are part of these government decision-making processes are opaque to public scrutiny.

What is known of these SSA decision-making processes is that:

"*SSA's Offices of the Chief Actuary and Budget also review the proposed changes to the Listings for the costs and savings. Once the final changes have been incorporated, the Agency prepares a cost-benefit analysis, which – according to SSA – can take 2 to 4 months.*" [53]

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[52] https://report.nih.gov/info_disease_burden.aspx;
Moses, H. et al. *JAMA*. 2015;313:174-189.

[53] https:oig.ssa.gov/sites/default/files/audit/full/pdf/A-01-15-50022.pdf

It is understood by this, that SSA likely 'scored' the cost-benefit analysis of their decisions during the final rule-making regarding whether (1) to add a headache disorders listing, and/or (2) to release existing crucial guidance to migraine claimants.

Since either of these decisions would be expected to impact the success of migraine SSDI claims, there is probable cause to assume that cost savings considerations may have driven the SSA decision-making process to discriminate against a specific class of claimants based on their disabilities (i.e. those with migraine).

The public has a right to know whether this is truly the case through SSA public disclosure of the 1,377 page(s) of withheld response documents, or any further documents withheld by SSA and related to the FOIA request.

h. The final rule-making is not eligible for judicial deference to the SSA Commissioner since it is "*contrary to constitutional right, power, privilege, or immunity*." [54]

i. It is an infringement of equal protection of the laws under Section 1 of the 14th amendment of the United States Constitution under "intermediate scrutiny" for SSA to discriminate based on highly gendered causes of disability.

Migraine susceptibility is strongly directed both by women's reproductive hormones and by genetic predisposition. Three quarters of Americans with disabling migraine are women. Mutations and variations of more than fifty genes are known to significantly increase migraine susceptibility, of which variations in at least nine genes are known to be sufficiently "penetrant" so as to determine the expression of migraine with extremely high likelihood in such affected individuals. The disabling traits of migraine are thereby intrinsically genetic and intrinsically gendered, and cannot be separated from this gender association.

Therefore, based on sex and immutable genetics, migraine belongs to a suspect class and the discriminatory consequences of SSA Sequential Evaluation policies, as noted above, are unconstitutional.

ii. It is an infringement of procedural due process under the 5th Amendment and under Section 1 of the 14th amendment of the United States Constitution for SSA to discriminate on the basis of disability.

SSA paycheck withholdings from potential claimants constitute federally-mandated insurance premium payments and confer upon potential

[54] 5 U.S.C. § 706(2)

claimants the right to claim monetary benefits.

"*...the law created a contributory insurance system, under which what in effect constitute premiums are shared by employees and employers. Consequently, in spirit at least, if not strictly and technically, the employee, who throughout his working life has contributed part of the premiums in the form of deductions from his wages or salary, should be deemed to have a vested right to the payments prescribed by the statutory scheme, which in effect comprises the terms of his insurance policy.*" [55]

SSA policies discriminating based on the cause of disabilities, as noted above, deprive selective claimants of protected property interests in significantly limiting the likelihood of success of their claims. Therefore, the discriminatory consequences of SSA Sequential Evaluation policies, as noted above, are unconstitutional.

3. Basis for appeal for SSA to discharge and refund the $2,908.00 FOIA fee.

a. SSA failed to notify me within the statutory requirement of 20 federal work days from the date of the FOIA request regarding whether SSA would comply with the FOIA request.

The fee letter was received 237 days following submission of the FOIA request, and the response letter was received 294 days following submission of the FOIA request.

Since SSA did not notify me in a timely manner within the specified FOIA "tolling period", SSA is not entitled to any fee for search or duplication of any documents.

The FOIA states [56]:

"Each agency, upon any request for records made under paragraph (1), (2), or (3) of this subsection, shall... (i) determine within 20 days (excepting Saturdays, Sundays, and legal public holidays) after the receipt of any such request whether to comply with such request and shall immediately notify the person making such request of such determination and the reasons therefor, and of the right of such person to appeal to the head of the agency any adverse determination...

(I) Except as provided in subclause (II), an agency shall not assess any search fees (or in the case of a requester described under clause (ii)(II) of this subparagraph, duplication fees) under this subparagraph if the agency has failed to comply with any time limit under paragraph (6).

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[55] Schmiedigen v. Celebrezze, 245 F. Supp. 825, 827 (D.C. 1965)
[56] https://www.foia.gov/foia-statute.html

(II)(aa) If an agency has determined that unusual circumstances apply (as the term is defined in paragraph (6)(B)) and the agency provided a timely written notice to the requester in accordance with paragraph (6)(B), a failure described in subclause (I) is excused for an additional 10 days. If the agency fails to comply with the extended time limit, the agency may not assess any search fees (or in the case of a requester is described under clause (ii)(II) of this subparagraph, duplication fees)."

b. The FOIA request was submitted, in part, to obtain guidance documents on disability evaluation procedures that SSA Acting Commissioner Carolyn W. Colvin has stated exist, and that SSA makes available to their DDS adjudicators.

These documents have been withheld from migraine claimants, and they would be instructive and valuable to such claimants in making their valid claims. This request therefore clearly pertains to legitimate SSA "*program-related purposes*".

As noted, "*the needed information will be used for a purpose which is directly related to the administration of a program under the Social Security Act*" [57]:

i. "*information needed to pursue some benefit under the* [Social Security] *Act*"

ii. "*information needed in connection with an activity which has been authorized under the* [Social Security] *Act.*"

The request is therefore not subject to the authority asserted by SSA in Section 1106 of the Social Security Act to charge a fee for fulfillment of the FOIA request.

c. I seek a full waiver of FOIA fees on the basis of statutory exemptions.

i. Under statute, fees for FOIA requests are limited to:

"*reasonable standard charges for document duplication when records are not sought for commercial use and the request is made by an educational or noncommercial scientific institution, whose purpose is scholarly or scientific research, or a representative of the news media.*" [58]

The documents I seek under the FOIA request are not sought for commercial use. I am employed as a Professor of Neurological Sciences by the Larner College of Medicine at the University of Vermont, an "educational or noncommercial scientific institution". I am a physician and research scientist pursuing scholarly research on migraine disability

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[57] 20 C.F.R. § 402.175; 42 U.S.C. § 402.170; 42 U.S.C. § 1306(c); https://www.ssa.gov/OP_Home/cfr20/402/402-0170.htm

[58] 5 U.S.C. § 552(a)(4)(A)(ii)(II)

relevant to the FOIA request [59].

ii. Under statute:

"*Documents shall be furnished without any charge or at a charge reduced below the fees established under clause (ii) if disclosure of the information is in the public interest because it is likely to contribute significantly to public understanding of the operations or activities of the government and is not primarily in the commercial interest of the requester.*" [60]

I am founding president of the AHDA, a national organization advocating on behalf of the interests of Americans with disabling headache disorders.

I seek the withheld response documents to improve claimant understanding of SSA operations, which is in the public interest of ensuring equitable and transparent implementation and application of the provisions of the Social Security Act.

d. The SSA sent the response letter with the fraudulent intent to shield SSA violations of law from public exposure.

The imposition of the $2,908.00 fee was apparently intended by SSA to discourage my seeking lawful release of the 1,377 page(s) of response documents in order to thwart public scrutiny of SSA violations of law, as noted above.

Accordingly, imposition of the fee cannot itself be lawful.

e. Finally, it is obviously and manifestly unconscionable for SSA to demand and assess a $2,908.00 fee for the release of no records relevant to the FOIA request.

4. Redress of claims:

a. I seek the immediate release of the 1,377 page(s) of withheld response documents cited in the response letter.

I also seek any additional relevant response documents prompted by the FOIA request language that SSA deleted from the FOIA request as cited in the response letter.

i. Americans with disabling migraine are entitled to know what guidance SSA currently provides to SSA adjudicators in evaluating migraine and headache disorders claims and impairments, and that would influence the allowance or denial of SSDI/SSI benefits.

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[59] Shapiro, RE. *Continuum* (Minneap Minn). 2012;18:900-4.
[60] 5 U.S.C. § 552(a)(4)(A)(iii)

ii. Americans with disabling migraine and other headache disorders are entitled to learn the specific reasons, arguments, and justifications upon which SSA has based their discriminatory and unlawful decisions, policies and practices:

1. That withhold existing disability evaluation guidance from the public.

2. That do not include a migraine and headache disorders listing in the Blue Book.

3. That ensure that some disabled Americans (with 'visible' disorders) have a significant advantage over other equally disabled Americans (with 'invisible' disorders) in qualifying for federal disability benefits, based solely on the types of their disabling diseases.

b. I seek immediate discharge and refund of the $2,908 FOIA fee.

"*The basic function of the Freedom of Information Act is to ensure informed citizens, vital to the functioning of a democratic society.*" [61]

In compliance with statute, I expect a full response to these appeals from SSA by September 23, 2019, twenty federal workdays from today. [62]

Thank you very much, in advance, for your prompt review of these appeals.

Sincerely,

Robert E. Shapiro

Robert E. Shapiro, MD, PhD.

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[61] https://www.foia.gov/

[62] 5 U.S.C. § 552(a)(6)(A)(ii)

Exhibit A:
FOIA response letter

SOCIAL SECURITY

Refer to:
S9H: SSA-2019-000087

July 26, 2019

Dr. Robert E. Shapiro
University of Vermont
1256 Whalley Road
Charlotte, VT 05445
Robert.shapiro@uvm.edu

Dear Dr. Shapiro:

I am responding to your October 5, 2018 Freedom of Information Act (FOIA) request for all documents, regardless of age, pertaining to the Social Security Administration's (SSA) assessment, evaluation, and decisions regarding inclusion or exclusion of a proposed listing for impairments due to migraine and other headache disorders in the SSA Listing of Impairments (Blue Book). These documents should relate to, but not be limited to, the 2013 to 2016 process of SSA rules-making, ANPRM, NPRM and final rules-making for revision of Medical Criteria for Evaluating Neurological Disorders listings (11.00 Neurological – Adult). You are also seeking all documents (i.e. from SSA Office of Disability Policy or other SSA offices), regardless of age, pertaining to, and/or informing, guidance as to how Listings of Impairments (e.g 11.02 Epilepsy) are to be appropriately utilized and interpreted (i.e. by SSA adjudicators and administrative law judges) in order to assess and determine medical equivalency with impairments attributed to, or caused by, migraine or other headache disorders, such as cluster headache.

Enclosed are two memorandums titled "2017 Fall Unified Agenda and Regulatory Plan 8-9-16" and "Pascrell Jr. Huntington's Disease 120513" responsive to your request as well as the 20 CFR Part 404 Revised Medical Criteria for Evaluating Neurological Disorders on the Federal Register's website at https://www.govinfo.gov/content/pkg/FR-2016-07-01/pdf/2016-15306.pdf.

I am withholding 1377 page(s) of the responsive documents, including the attachments mentioned in the "2017 Fall Unified Agenda and Regulatory Plan 8-9-16" based on FOIA Exemption 5 that protects the deliberative process. FOIA Exemption 5 protects advice, opinions, recommendations, predecisional discussion, and evaluative remarks that are part of the government decision-making process. Release of such predecisional advisory communications would harm the quality of agency decision-making and the policy of encouraging frank, open discussion among agency personnel before making a decision (5 U.S.C. §552(b)(5)).

The general purposes of the deliberative process privilege are to prevent injury to the quality of agency decisions and to protect government agencies' decision-making processes. The deliberative process privilege allows agencies to freely explore alternative avenues of action and to engage in internal debates without fear of public scrutiny (*Missouri ex rel. Shorr v. United States Army Corps of Engineers*, 147 F.3d 708, 710 (8th Cir. 1998)). Exemption 5 protects not

merely documents, but also the integrity of the deliberative process itself, where the exposure of that process could result in harm. We believe that disclosure of the information at issue could cause foreseeable harm to the agency's decision-making processes.

Pursuant to FOIA Exemption 6 (5USC § 552(b)(6)), I have deleted personal information about other individuals from the enclosed documents. When we receive a request from a member of the public to release personal information about another individual from our records, we must balance the individual's privacy interest in withholding the information against the public interest in disclosing the information. We must determine whether disclosure would affect a personal privacy interest. Individuals clearly have a substantial personal privacy interest in the personal details furnished to the government. On the other hand, the only public interest we must consider is whether the information sought would shed light on the way an agency performs its statutory duties. We may not consider the identity of the requester or the purpose for which the information is requested. While the public has an interest in knowing how the Social Security Administration administers the Social Security Act, disclosing records containing personal information about named individuals would not shed light on how the agency performs its statutory duties. Therefore, disclosing this information would be a clearly unwarranted invasion of personal privacy, and the FOIA (5 U.S.C. § 552(b)(6)) does not require disclosure.

If you have questions, or would like further assistance with your request, you may contact our FOIA Public Liaison by email at FOIA.Public.Liaison@ssa.gov; by phone at 410-965-1727, by choosing Option 2; or facsimile at 410-966-0869.

You may also contact the Office of Government Information Services (OGIS) at the National Archives and Records Administration for dispute resolution services. OGIS is an entity outside of the Social Security Administration that offers mediation services to resolve disputes between FOIA requesters and Federal agencies. The contact information for OGIS is as follows: Office of Government Information Services, National Archives and Records Administration, 8601 Adelphi Road – OGIS, College Park, MD 20740-6001; email at ogis@nara.gov; telephone at 202-741-5770; toll-free at 1-877-684-6448; or facsimile at 202-741-5769.

If you disagree with this decision, you may file a written appeal with the Executive Director for the Office of Privacy and Disclosure, Social Security Administration, G-401 WHR, 6401 Security Boulevard, Baltimore, Maryland 21235. Your appeal must be postmarked or electronically transmitted to FOIA.Public.Liaison@ssa.gov within 90 days of the date of our response to your initial request. Please mark the envelope or subject line with "Freedom of Information Appeal."

Sincerely,

Mary Ann Zimmerman

Mary Ann Zimmerman
Freedom of Information

Enclosure

Exhibit B:
FOIA fee letter

SOCIAL SECURITY

Refer to:
S9H: SSA-2019-000087 May 29, 2019

Dr. Robert E. Shapiro
University of Vermont
1256 Whalley Road
Charlotte, VT 05445

Dear Dr. Shapiro:

This letter is in response to your October 5, 2018 Freedom of Information Act (FOIA) request for all documents, regardless of age, pertaining to the Social Security Administration's (SSA) assessment, evaluation, and decisions regarding inclusion or exclusion of a proposed listing for impairments due to migraine and other headache disorders in the SSA Listing of Impairments (Blue Book).

Before we proceed, I wanted to inform you of the fees associated with processing your request and inform you that your request presents unusual circumstances because there is a need to search for and collect records from Social Security components or field offices.

Please know that we have determined that your request is for non-program related purposes and therefore, the agency should charge the full costs it incurs when providing you this information. *See* 20 C.F.R. § 402.175. Section 1106 of the Social Security Act (Act) gives the agency the authority to charge full costs for responding to information requests that are for non-program related purposes, regardless of the fee provisions of FOIA. 42 U.S.C. § 1306(c). Because the agency is invoking its authority under section 1106 of the Act, your status as a FOIA requester is irrelevant and the agency will charge you full costs. Accordingly, the agency will charge you for search, duplication, and review it undertakes to attempt to fulfill your request. *See* 20 C.F.R. § 402.175(c).

When our employees search for records, we charge the following hourly rate depending on the grade of the employee:

- $16.00 (GS-1 through GS-8)
- $33.00 (GS-9 through GS-14)
- $59.00 (GS-15 and above)

We estimate the cost to provide this information is $2908.00, which includes 76.5 hours of search and review time at $33.00 per hour and 6.5 hours of search and review time at 59.00 per hour. If there is a duplication fee, we will bill you. In addition, according to our regulations at 20 C.F.R. § 402.175(e), we may charge a fee for search time even if we are unable to locate any responsive records or the records are exempt from disclosure. Please know this fee is an estimate, especially since we are still waiting on one of our regions to provide their preliminary data.

If you want us to proceed with your request, **you must let us know**. You may also narrow the scope of your request or set a limit on the amount you are willing to pay. You may pay by check or money order payable to SSA or by credit card (MasterCard, Visa, Discover, American Express, or Diner's Club). To pay by credit card, complete and sign the enclosed form. Include your credit card number and expiration date.

You may submit payment information by email to FOIA.Public.Liaison@ssa.gov or by mail to my attention at the Social Security Administration, Office of the General Counsel, Office of Privacy and Disclosure, G-401 WHR, 6401 Security Boulevard, Baltimore, MD 21235. Please annotate the case number above on your payment. **If we do not receive payment within ten business days from the date of this letter, we will administratively close your request**. You will not receive a separate notification that we closed your request.

If you have questions, or would like further assistance with your request, you may contact our FOIA Public Liaison by email at FOIA.Public.Liaison@ssa.gov; by phone at 410-965-1727, by choosing Option 2; or facsimile at 410-966-0869.

You may also contact the Office of Government Information Services (OGIS) at the National Archives and Records Administration for dispute resolution services. OGIS is an entity outside of SSA that offers mediation services to resolve disputes between FOIA requesters and Federal agencies. The contact information for OGIS is as follows: Office of Government Information Services, National Archives and Records Administration, 8601 Adelphi Road – OGIS, College Park, MD 20740-6001; email at ogis@nara.gov; telephone at 202-741-5770; toll-free at 1-877-684-6448; or facsimile at 202-741-5769.

If you disagree with this decision, you may file a written appeal with the Executive Director for the Office of Privacy and Disclosure, Social Security Administration, G-401 WHR, 6401 Security Boulevard, Baltimore, Maryland 21235. Your appeal must be postmarked or electronically transmitted to FOIA.Public.Liaison@ssa.gov within 90 days of the date of our response to your initial request. Please mark the envelope or subject line with "Freedom of Information Appeal."

Sincerely,

Monica Chyn
Acting Freedom of Information Officer

Enclosure

Exhibit C:
FOIA submission receipt

Shapiro, Robert E.

From: admin@foiaonline.gov
Sent: Friday, October 05, 2018 5:14 PM
To: Robert Shapiro
Subject: FOIA Request SSA-2019-000087 Submitted

This message is to confirm your request submission to the FOIAonline application: View Request. Request information is as follows:

- Tracking Number: SSA-2019-000087
- Requester Name: Dr. Robert E Shapiro
- Date Submitted: 10/05/2018
- Request Status: Submitted
- Description: I seek all documents, regardless of age, pertaining to SSA assessment, evaluation, and decisions regarding inclusion or exclusion of a proposed listing for impairments due to migraine and other headache disorders in the SSA Listing of Impairments (Blue Book). These documents should relate to, but not be limited to, the 2013 to 2016 process of SSA rules-making, ANPRM, NPRM and final rules-making for revision of Medical Criteria for Evaluating Neurological Disorders listings (11.00 Neurological – Adult). These documents should include, but be not limited to, all relevant correspondence, emails, memoranda, drafts, cost-benefit analyses, public comments, and related guidance documents, including those documents from and between all relevant SSA offices (i.e. Office of Regulations and Reports Clearance, Office of Disability Policy, Office of General Counsel, Offices of the Chief Actuary and Budget, etc.), as well as those document from and between SSA offices and offices of other Federal Government agencies. I also seek all documents (i.e. from SSA Office of Disability Policy or other SSA offices), regardless of age, pertaining to, and/or informing, guidance as to how Listings of Impairments (e.g 11.02 Epilepsy) are to be appropriately utilized and interpreted (i.e. by SSA adjudicators and administrative law judges) in order to assess and determine medical equivalency with impairments attributed to, or caused by, migraine or other headache disorders, such as cluster headache.

Exhibit D:
FOIA fee receipt

Shapiro, Robert E.

From: ^FOIA Public Liaison <FOIA.Public.Liaison@ssa.gov>
Sent: Thursday, June 06, 2019 8:40 AM
To: Shapiro, Robert E.
Subject: RE: [EXTERNAL] FW: Fee Letter

Dr. Shapiro,

Thank you for your payment of $2,908.00.
Please keep in mind that this is only a fee estimate. We will let you if the final fee is more than $2908.00.

Thank you,

Office of Privacy and Disclosure
Office of General Counsel

FOIA PA Officers
Office of Privacy and Disclosure
6401 Security Boulevard
617 Altmeyer Building
Baltimore, MD 21235
410-965-1727

From: Shapiro, Robert E. <Robert.Shapiro@uvmhealth.org>
Sent: Wednesday, June 05, 2019 2:19 PM
To: ^FOIA Public Liaison <FOIA.Public.Liaison@ssa.gov>
Subject: RE: [EXTERNAL] FW: Fee Letter

Please find the attached credit card payment form.

Please send me a return email acknowledging receipt of the $2,908.00 payment.

Thanks very much,

Robert E. Shapiro, MD, PhD

Professor
Department of Neurological Sciences
Robert Larner, MD, College of Medicine
University of Vermont Medical Center
Arnold 2442A, University Health Center, 1 South Prospect St., Burlington, VT, 05401-3456
Phone: 802-847-6656 / FAX: 802-847-4918
Email: robert.shapiro@uvm.edu *or* robert.shapiro@uvmhealth.org
Skype: robert.shapiro802 / Twitter: @headachedoc
http://www.med.uvm.edu/neuro/bio?BioID=23183

From: ^FOIA Public Liaison [mailto:FOIA.Public.Liaison@ssa.gov]
Sent: Wednesday, June 05, 2019 2:06 PM
To: Shapiro, Robert E. <Robert.Shapiro@uvmhealth.org>
Subject: RE: [EXTERNAL] FW: Fee Letter

Dr. Shapiro,

We apologize for not attaching the credit card form in our email. The form is attached to this email. At this time, we are unable to estimate the of time of delivery of the requested documents. You will be receiving the documents on a disk.

Thanks

FOIA PA Officers
Office of Privacy and Disclosure
6401 Security Boulevard
617 Altmeyer Building
Baltimore, MD 21235
410-965-1727

From: Shapiro, Robert E. <Robert.Shapiro@uvmhealth.org>
Sent: Tuesday, June 04, 2019 3:34 PM
To: ^FOIA Public Liaison <FOIA.Public.Liaison@ssa.gov>
Subject: [EXTERNAL] FW: Fee Letter

To the FOIA Team

On 5/30, I received the email below with attached Fee Letter dated 5/29 regarding FOIA request **S9H: SSA-2019-000087**.

The Fee Letter indicates that it was accompanied by a credit card form for payment, but the form was not enclosed.

Please email me an appropriate credit card form for payment.

Further, the Fee Letter estimates the Fee to be $2,908, but that the final Fee could be different. Please advise if the final Fee is now different from $2,908.

Finally, once the Fee has been paid, what is the estimated time until delivery of the documents? Also, will they be delivered electronically or in paper form?

Thank you,

Robert E. Shapiro, MD, PhD

Professor
Department of Neurological Sciences
Robert Larner, MD, College of Medicine
University of Vermont Medical Center
Arnold 2442A, University Health Center, 1 South Prospect St., Burlington, VT, 05401-3456
Phone: 802-847-6656 / FAX: 802-847-4918
Email: robert.shapiro@uvm.edu *or* robert.shapiro@uvmhealth.org
Skype: robert.shapiro802 / Twitter: @headachedoc
http://www.med.uvm.edu/neuro/bio?BioID=23183

From: no-reply@foiaonline.gov [mailto:no-reply@foiaonline.gov]
Sent: Thursday, May 30, 2019 11:45 AM
To: Robert Shapiro <Robert.Shapiro@uvm.edu>
Subject: Fee Letter

Please do not reply directly to this email correspondence. If you have an account with FOIAonline, you can correspond directly with us by logging into your account. If you need to correspond with us regarding your FOIA request but do not have an account with FOIAonline, please send your correspondence to FOIA.Public.Liaison@ssa.gov. Please include your FOIA tracking number in your email.

Sincerely,

The FOIA Team

Social Security Administration

Exhibit E:
FOIA response letter – Huntington attachment

BILL PASCRELL, JR.
9th District, New Jersey

2370 RAYBURN HOUSE OFFICE BUILDING
WASHINGTON, DC 20515
(202) 225-5751
(202) 225-5782 FAX

ROBERT A. ROE FEDERAL BUILDING
200 FEDERAL PLAZA, SUITE 500
PATERSON, NJ 07505
(973) 523-5152
(973) 523-0637 FAX

http://pascrell.house.gov
bill.pascrell@mail.house.gov

COMMITTEE ON WAYS AND MEANS
SUBCOMMITTEE ON HEALTH

COMMITTEE ON THE BUDGET

Congress of the United States
House of Representatives

Thursday, December 05, 2013

Carolyn W. Colvin
Acting Commissioner Social Security Administration
6401 Security Blvd.
Baltimore, MD 21235-0001

Dear Acting Commissioner Colvin,

I understand that the Social Security Administration may be moving to update the severely outdated listings used to determine disability for individuals with Huntington's disease. While this is encouraging news, I am writing today to ask for a meeting for the Huntington's Disease Society of America to discuss these pending updates and ensure they accurately address the concerns of the Huntington's disease community.

As you know, Huntington's disease is a severe degenerative neurological disease that results in total cognitive, physical, and emotional impairment. After the disease's onset, often during an individual's prime working years, those with Huntington's will lose the ability to work and live independently. I, along with Representative Kinzinger, have introduced legislation in this Congress to alleviate the stress and burdens that Huntington's disease families face everyday. The Huntington's Disease Parity Act of 2013 (H.R. 1015) seeks updated guidelines regarding the definition of Huntington's disease to access Social Security Disability benefits, as well as to eliminate the two-year waiting period to become eligible for Medicare coverage. I am looking forward to positive policy changes that will make it easier for Huntington's disease families to navigate the benefits process.

I am pleased at the steps that the Social Security Administration has taken to begin the process of updating the medical guidelines associated with Huntington's disease. I would appreciate a meeting at your earliest convenience to meet with the Huntington's Disease Society of America and their medical experts to ensure that the needs of Huntington's disease families are being met.

I look forward to hearing back on this request shortly, and am happy to answer any questions you may have.

Sincerely,

Bill Pascrell Jr.

Bill Pascrell, Jr.
Member of Congress

Huntington's Disease Society of America

December 17, 2014

Carolyn W. Colvin
Commissioner of Social Security
P.O. Box 17703
Baltimore, MD 21235-7703

Dear Acting Commissioner Colvin,

On behalf of the Huntington's Disease Society of America (HDSA), the largest national advocacy organization representing families affected by Huntington's disease (HD), I write today to request a meeting in January 2014 regarding the guidelines used to evaluate the Social Security Disability (SSD) applications submitted by persons with HD. As SSA moves to revise the Blue Book Neurological listings, it is vital that the unique needs of individuals with HD be taken into account.

Individuals with HD are Precisely whom SSD is Intended to Help

HD is a hereditary, degenerative brain disorder that slowly diminishes an individual's ability to walk, talk and reason. HD strikes most often exactly during the time that individuals need their Social Security disability benefits – their prime working years. There is no treatment or cure for the disease but there is an identified gene defect. Those who inherit this genetic defect will develop HD. About 30,000 Americans have HD and are in the process of losing, or have already lost, the ability to work and live independently. Another 200,000 Americans are considered 'at-risk', and have a fifty percent chance of inheriting HD from their affected parent.

Individuals with HD are Unique

People with HD applying for SSD are routinely denied benefits due to the SSA's outdated and medically inaccurate guidelines, which were written nearly 30 years ago. Today, we know that the debilitating cognitive and behavioral symptoms of HD begin at least a decade before the visible, physical effects can be observed. The SSD guidelines to evaluate HD applications are inadequate and currently lead to difficulties, delays and denials in receiving benefits. We are encouraged that these guidelines are being updated to reflect modern medical advancements and understanding of this disabling disease – but would appreciate the opportunity to discuss these guidelines to ensure they meet the needs of our community.

Some difficulties in obtaining benefits faced by the HD community can be categorized as follows:

- The absence of readily apparent dysfunction especially if the chorea or movement disorder has not yet appeared or is the more subtle symptoms such as loss of fine motor coordination and the slowing of eye movements;

- The belief on the part of the DDS worker that the applicant and his or her symptoms will improve with treatment;
- The relative youth of the applicant, especially for individuals applying in their thirties and forties;
- The patient's lack of insight (which is a symptom of the disease itself) about the progression of the disease with the result that the affected individual is not able to give an accurate assessment of his or her condition;
- Difficulty, given the often subtle onset of symptoms, in pinpointing exactly when a person with HD first became disabled;
- Lack of familiarity with Huntington's disease on the part of many DDS workers

These issues can, and should, be addressed in a revised listing in the Blue Book. An improved listing would save time, money, resources and emotional energy on the part of the Social Security Administration and the individuals and families it serves who suffer with the effects of Huntington's disease. As the organization that represents individuals with Huntington's disease, HDSA must be involved in this process.

I look forward to hearing back from you regarding a meeting in January about how the Neurological listings can be revised to better serve individuals disabled by HD.

Sincerely,

Louise Vetter
Chief Executive Officer
Huntington's Disease Society of America

Exhibit F:
FOIA response letter - United Agenda attachment

SOCIAL SECURITY

Office of Legislation and Congressional Affairs

MEMORANDUM

Date: August 9, 2016 Refer To:

To: See below

From: Erik Hansen /s/
Associate Commissioner
for Legislative Development and Operations

Subject: Fall Regulatory Plan and Unified Agenda

REPLY REQUESTED BY: August 16, 2016

The Office of Management and Budget (OMB) is requesting that federal agencies submit their 2017 Unified Agenda and Regulatory Plans to OMB shortly. To meet OMB's deadline, we require components to provide information on their proposed 2017 regulatory initiatives by **COB August 16, 2016.**

Unified Agenda

The Unified Agenda of Federal Regulatory and Deregulatory Actions ("Unified Agenda") encompasses regulations currently under development for the coming year, including priority and non-priority rules. The goal of the Unified Agenda is to map out the planned trajectory of agencies' active rules over a 12-month period, including realistic publication dates.

Regulatory Plan

The Regulatory Plan is a subset of the Unified Agenda, comprising regulatory initiatives of significant importance to the agency. OMB looks to the Regulatory Plan to present agencies' most notable policies. Essentially, these are the "flagship" rules for the agency in the coming year.

Historical Context for Unified Agenda and Regulatory Plan

In the past, agencies included all partially developed or in-process regulations in their Unified Agendas, irrespective of their stage of rulemaking or likelihood to publish in the next 12 months. While Regulatory Plans did include important rules, they did not always represent agencies' top priorities.

OMB Change for Unified Agenda and Regulatory Plan

This year, OMB outlined a new direction for the Unified Agenda and Regulatory Plan. Rather than including all in-process agency rules in the Unified Agendas, whether they are likely to publish or not in the year, OMB has requested that agencies should include only those regulatory actions they believe could realistically publish during the upcoming year. OMB has also directed agencies not to simply list rules in the Agenda. Instead, OMB has requested that the Agenda should be connected to the agency's strategic or other priorities.

Similarly, OMB has asked that Regulatory Plans include only those Unified Agenda rules that are of utmost importance to the agency. The Plan will be the central core of the agency's defined regulatory goals for 2017.

Whereas previously OMB accepted agency Unified Agendas and Regulatory Plans with minimal comment, this year OMB staff will be working more closely with agencies to ensure that OMB 1) understands the agencies' policy goals and 2) concurs that the rules we present in the Agenda and Plan would achieve those goals.

Unique Challenges for 2017

The upcoming year poses unique challenges for agency regulatory publication. Because of the change in Presidential Administration, OMB will not begin accepting regulatory actions for review until around April 2017. Historically, OMB accepts at most three SSA rules at a time for review, and possibly fewer if one of those rules is lengthy, complex, or politically sensitive. As always, OMB's allotted review time will be 90 days.

Given the anticipated late start to the 2017 regulatory cycle, the limitation on the number of rules OMB will accept simultaneously from SSA, and the potentially lengthy OMB review period, we can realistically expect to publish approximately 9-10 regulatory actions (proposed, final, or a combination of the two) in 2017. This restricted regulatory publication schedule compels the agency to carefully plan our Unified Agenda and Regulatory Plan for the year to ensure the best outcome for supporting the agency's goals.

SSA Component Regulatory Submissions

DCLCA is asking components to provide submissions for the 2017 Unified Agenda and Regulatory Plan. When preparing your submissions, please use the following attached documents:

- **Tab A – Inactive SSA Rules.** DCLCA has prepared a chart of all "inactive" SSA rules. For the purpose of completing this assignment, "inactive" means all SSA rules that are not on the 2016 regulatory priority plan agreed on by SSA and OMB. The inactive rules are sub-divided by category (Medical Listing; Adjudication Process Improvement; Improving the Disability Process; Bipartisan Budget Act; Enhancing Public Service; Privacy Act Exemption; and SSA Administrative).

- **Tab B – Rules' ROCIS Information.** This document contains the official OMB summary for every SSA regulation in ROCIS, OMB's online system. This document includes information for both 2016 rules and the inactive rules.

- **Tab C – Unified Agenda-Regulatory Plan Submission Form**. This document contains charts components are to complete for their Unified Agenda and Regulatory Plan submissions, and accompanying instructions for completion.

When deciding which rules to provide for the Unified Agenda and Regulatory Plan, components may find it helpful to review the Inactive Rules chart in Tab A, and to then copy and paste information, as appropriate, from the corresponding ROCIS document in Tab B. Components may also choose to provide information about new rules that are not currently documented in Tabs A or B.

Notes

- Components should use only Tab C to document the rules they wish to submit for the Unified Agenda and Regulatory Plan. For ease of use, the last page of Tab C contains a submission form with blank charts for both parts of the assignment.

- While the agency does not need to restrict our Unified Agenda to 10 regulations, 9-10 regulatory actions is the realistic 2017 publication figure for the agency. Accordingly, we encourage you to select those rules for your component that 1) are your most important priorities and 2) have a realistic chance of publishing in 2017.

- While we anticipate OMB will begin accepting rules for review around April 2017, they will only accept a maximum of three rules at a time. This means we cannot choose April 2017 as the starting date for every rule. Within your component, please coordinate and make sure to stagger submission dates throughout the remainder of 2017.

- OMB has committed to collaborating with SSA on the completion of the three ODAR CARES regulatory initiatives (Ensuring Program Uniformity at the Hearing and Appeals Council Levels of the Administrative Review Process; Revisions to Rules of Conduct and Standards of Responsibility for Appointed Representatives; and Medical Sources). OMB will not accept any other regulations for late fall 2016 or early 2017.

Responses

Components should complete the charts in Tab C to provide the requested information, along with the name of a contact person, to ^OR Controls. Responses are due **COB Tuesday, August 16, 2016.** Because of the work we must do after receiving your responses and the impending due date to OMB, we cannot extend this deadline.

Please direct any questions to Faye I. Lipsky (410-965-8783, faye.lipsky@ssa.gov), Office Director, [redacted]

Thank you.

Attachments:
Tab A – Inactive SSA Rules
Tab B – All Rules' ROCIS Information
Tab C – Unified Agenda-Regulatory Plan Submission Form

Addressees:
Deputy Commissioner for Budget, Finance, Quality and Management
Deputy Commissioner for Disability Adjudication and Review
Deputy Commissioner for Operations
Deputy Commissioner for Retirement and Disability Policy
Acting Inspector General
General Counsel

cc:
Chief Actuary
Deputy Commissioner for Communications
Deputy Commissioner for Human Resources
Deputy Commissioner for Legislation and Congressional Affairs
Deputy Commissioner for Systems
Chief Strategic Officer

Exhibit G:
SSA Q & A 09-036 (12/15/2009)

National

Question & Answer

Tracking number: 09-036

This revises Q&A 09-025

Only active Q&As may be used as guidance in the adjudication of a current claim.

Brief Question: **Please provide guidance regarding the evaluation of migraine headaches.**

Detailed Question:

The regulations state that we cannot establish a disabling condition based on symptoms alone. According to the medical literature, there are no laboratory findings or clinical signs to substantiate the presence of migraine headaches in most cases. The diagnosis of migraine headache is usually established through patients' reported symptoms (pain, photophobia, nausea). Previous guidance from the Office of Disability from the early 1990's stated that, although migraine headaches that are disabling for 12 continuous months in spite of treatment are extremely rare, there are some cases that do not respond to treatment. The guidance said to consider whether the impairment medically equals listing 11.03 based on "altered awareness."

Our questions are:

What criteria should we use to determine that migraine headaches are a medically determinable impairment (MDI)? Is a diagnosis from an acceptable medical source sufficient, even if it is based only on a claimant's reported symptoms? If not, what evidence establishes the MDI?

If we use listing 11.03 to evaluate migraine headaches, should we use POMS DI 24580.001/Social Security Ruling (SSR) 87-06 to evaluate migraine headaches? If so, what constitutes appropriate treatment and an ongoing treatment relationship?

The POMS/SSR also say that we need a description of a seizure from professional observation or a third party. Does this guidance apply to migraine headaches?

The POMS/SSR also say that we need a record of anticonvulsant blood levels in every case before we can allow it unless there is convincing evidence that subtherapeutic drug levels are due to abnormal absorption or metabolism and the prescribed drug dosage is adequate. Is there an analogous medically acceptable way to determine if an individual is taking headache medications appropriately? If not, how should we assess compliance with treatment?
What is "altered awareness" and how is it measured?

Answer:
Because of significant changes in the diagnosis and treatment of migraine headaches since we provided guidance in memorandums from the early 1990's, we are rescinding that guidance and temporarily replacing it with the guidance in this Q & A while we prepare proposed updates to the neurological listings. However, as we explain below, there is little change in the guidance we originally provided.

Under our general policy, you cannot establish the existence of any MDI based solely on a diagnosis in the evidence or on a claimant's reported symptoms. There must be clinical signs or laboratory findings to support the finding.
A diagnosis of migraine headaches requires a detailed description from a physician of a typical headache event (intense headache with more than moderate pain and with associated migraine characteristics and phenomena) that includes a description of all associated phenomena; for example, premonitory symptoms, aura, duration, intensity, accompanying symptoms, and effects of treatment. The diagnosis should be made only after the claimant's history and neurological and any other appropriate examinations rule out other possible disorders that could be causing the symptoms. There are other clinically accepted indicators of the diagnosis, including:

Headache event that lasts from 4 to 72 hours if untreated or unsuccessfully treated.
Two of the following: Unilateral, pulsating (throbbing) quality; moderate (inhibits but does not wholly prevent usual activity) or severe (prevents all activity) pain intensity, worsened by routine physical activity (or

causing avoidance of activity).
At least one of the following during the headache: Nausea, vomiting, photophobia, or phonophobia.

Once other possible causes have been ruled out and a pattern has been established, we consider the foregoing findings reported by a physician to be "signs" that establish the existence of migraine headaches as an MDI. This is consistent with the way we establish the existence of some mental disorders and other physical disorders that are characterized by complaints reported by acceptable medical sources based on their examinations.

As in our earlier guidance regarding migraine headaches, we continue to recognize that migraine headaches will rarely prevent a person from working for a continuous 12 months but that there are exceptions. Likewise, listing 11.03 (Epilepsy - nonconvulsive epilepsy) is still the most analogous listing for considering medical equivalence. However, the guidance in POMS DI 24580.001/ SSR 87-06 is specific to epilepsy and not applicable to the evaluation of migraine headaches. We do not consider treatment non-compliance or therapeutic levels of medication in the blood because, unlike treatment for epilepsy, which seeks to maintain a steady level of medication in the blood, there is no such standard of care in the treatment of migraine headaches. Also, therapeutic blood levels for migraine medication have not been established. Nor do we require a professional observation or third-party description of a migraine headache event, although such observations are helpful. We require a professional observation or third-party description of a seizure partly because the person having the seizure is unaware of it and cannot describe how s/he looks during a seizure. This is not the case for migraine headaches.
It may be helpful to review the essential components of listing 11.03 as they may be related to migraine headaches:

"Documented by detailed description of a typical" headache event pattern
"Including all associated phenomena"; for example, premonitory symptoms, aura, duration, intensity, accompanying symptoms, treatment.
"Occurring more frequently than once weekly." Count characteristic headache events.

"In spite of at least 3 months of prescribed treatment." Inapplicable, as we explain above.
"With alteration of awareness." This means a condition of being inattentive, or not cognizant of one's surroundings and external phenomena as well as one's personal state. Many psychotropic and neuroleptic medications used for treating migraines can produce sedation, confusion, or inattention. However, it is not necessary for a person with migraine headaches to have alteration of awareness as long as s/he has an effect (e.g., one or more of the problems described in the next bullet) that significantly interferes with activity during the day.
"Significant interference with activity during the day." Same meaning as in listing 11.03. May be the result, e.g., of a need for a darkened, quiet room, lying down without moving, or a sleep disturbance that impacts on daytime activities.

Did this document help answer your question?

Category: Medical Policy
Subcategory: Neurological
Purpose: Policy Clarification
Answered by: ODP

Posted: **Tue 12/15/2009**
Responsible CO Component: **ODP**
Reference:
Link to reference:

Link to this section:
http://policynet.ba.ssa.gov/pnqa.nsf/links/09-036This%20revises%20Q&A%2009-028

Exhibit H:
AHDA letter 1

Medical Criteria for Evaluating Headache Disorders: A Proposed Revision of the Social Security Administration Listing of Impairments (Blue Book).

Robert E. Shapiro, MD, PhD
Professor of Neurological Sciences
University of Vermont College of Medicine
Arnold 2435B, University Health Center
1 South Prospect St.
Burlington, VT, 05401
Phone: 802-847-6656
FAX: 802-847-4918
Email: robert.shapiro@uvm.edu

President
Alliance for Headache Disorders Advocacy
(http://www.allianceforheadacheadvocacy.org/)

comprised of:
Alliance for Patient Access
American Academy of Neurology
American Headache Society
Clusterbusters
Headache Cooperative of New England
Headache Cooperative of the Pacific
Migraine Research Foundation
Miles for Migraine Races
National Headache Foundation
National Migraine Association / MAGNUM
Ohio Headache Association
PFO Research Foundation

March 15, 2013

Brief Background:
Headache disorders, including migraine, trigeminal autonomic cephalalgias, cranial neuralgias, post-traumatic headaches, etc., are among the most common medical conditions and a source of tremendous collective and individual disability and impairment.

Prevalence:
Approximately half of Americans will experience some type of headache disorder this year and more than 20% of Americans will experience some form of migraine. Migraine is 3 times more prevalent in women compared to men, with a particular burden placed on women during the ages of child-bearing and principal employability. Approximately 4% of Americans experience some type of headache at least 15 days per month, with up to one half of them experiencing chronic migraine. US annual prevalence for cluster headache is approximately 400K Americans.

Disability Burden:
Data from the 2010 Global Burden of Disease Study indicate that migraine alone accounts for 30% of the total disease burden (DALYs) and more than 50% of the disability burden (YLDs) attributable to all neurological disease worldwide (Murray et al. *Lancet* 2012;380:2197, Vos et al. *Lancet* 2012;380:2163). Migraine is estimated to be the 7th ranking single cause of all disease-associated disability (YLDs) worldwide (Steiner et al. *Headache* 2013;53:227). A US population-based study estimated that total US lost work economic productivity due to all headache disorders was more than 4 times greater due to presenteeism ($16.4B/year), than due to absenteeism ($3.6B/year) (Stewart et al. *JAMA* 2003;290:2443).

A Norwegian population-based study found that individuals with headaches of any kind occurring 15 or more days per month take an average of 14 lost work days due to absenteeism annually, whereas 20% of such individuals take at least 8 weeks of sick leave per year (Fiane et al. *Cephalalgia* 2006;26:960). On average, US workers with 15 or more days with migraine headache per month lose 5.7 hours of work productivity per week, comprising an average loss of approximately 14% of total productivity for each of these workers (Stewart et al. *JOEM* 2010;52:8). Americans with migraine are also less likely to be employed in correlation with the frequency of their days with headache (37% full-time employed if 15 or more headache days per month vs. 48% full-time employed if 3 or fewer headache days per month). However, workers with migraine occurring fewer than 15 days per month may also sustain substantial lost work if the severity of the pain and associated symptoms is very great.

Overall, approximately 10% of Americans with episodic migraine (i.e. 14 days or fewer days per month) and 20% of Americans with chronic migraine (i.e. 15 or more days per month) report being "occupationally disabled" (Manack et al. *Curr Pain Headache Rep* 2011;15:70). Accepting these estimates, and considering the relative prevalence of migraine forms across the approximately 200M Americans between the ages of 18 and 65 years, perhaps 3M Americans

may be occupationally disabled by migraine, either alone or in combination with other co-morbid disabling conditions such as psychiatric, pain, respiratory, or cardiovascular disorders. It is not possible at this time to estimate how many individuals might be occupationally disabled due to migraine alone. Additionally, multiple other disabling headache disorders, such as chronic cluster headache, post-traumatic headache, trigeminal neuralgia, etc., certainly increase the prevalence of occupationally disabled Americans, perhaps by hundreds of thousands of individuals.

Headache Disorders Blue Book Listing:

We propose that the Social Security Administration Listing of Impairments be revised to include a listing that would encompass the impairments arising from headache disorders, either occurring alone or in combination with other co-morbid disabling conditions.

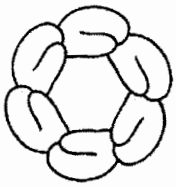
Proposed Draft Blue Book Listing:

"H. *Headache Disorders, including migraine, trigeminal autonomic cephalalgias, cranial neuralgias, and related disorders.* The degree of impairment due to headache disorders will be determined according to the frequency, duration, severity, and sequelae of symptomatic attacks and their impacts on functional activities. Migraine and other primary headache disorders are not typically associated with clear or reliable diagnostic findings on physical examination, and no validated biomarkers, imaging abnormalities, or laboratory findings are typically diagnostic of the diseases. Whenever appropriate, attributed diagnoses should be consistent with the clinical diagnostic criteria of the current edition of the *International Classification of Headache Disorders* (ICHD). A detailed description of the individual's typical or idiosyncratic attack or attack pattern of headache disorder is required. Such descriptions may include, but may not be limited to, the frequency, duration, and presence or absence of (a) premonitory symptoms, (b) 'aura' symptoms of disturbances of vision, skin sensation, language, strength, coordination, or vestibular function, (c) location, severity, duration, and qualities of eye, ear, nose, mouth, face, jaw, head, neck, or shoulder pain, (d) amplified, distorted, or pain-inducing sensation to light, sound, touch, movement, smell, or taste, (e) autonomic disturbances including nausea, vomiting, abdominal pain, gastroparesis, diarrhea, constipation, increased lacrimation, ptosis, peri-orbital edema, pupillary abnormalities, rhinorrhea, sweating, or nasal/sinus symptoms, or (f) disturbances of cognition, affect, concentration, language, motivation, attention, agitation, or tolerance of stressful or social environments. To establish a medically determinable impairment due to a headache disorder, an individual must submit supportive documentation of the frequency of impairing symptoms of that disorder. Such documentation may include data from symptom diaries, clinical or functional questionnaire records, medical records, reporting health care provider attestations and documentation, and other sources of ancillary information such as the frequency and nature of evaluations and treatments in emergency departments or other clinical settings. Evaluation of the severity and disability burden of headache disorders may also include, but would not require, consideration of data from validated survey instruments, such as,

but not limited to, the Headache Impact Test-6 (HIT-6), the Migraine Disability Assessment Test (MIDAS), the Henry Ford Headache Disability Inventory (HDI), or the Migraine-Specific Quality of Life Questionnaire (MSQ). Where documentation shows that the frequency of use of analgesic medications may have worsened the frequency or severity of migraine or other headache disorder, as in medication adaptation headache or analgesic-overuse headache, this fact should not be considered adversely in the overall assessment of impairment. When a history of physical or other traumatic or abusive experiences, or of co-morbid medical conditions, including psychiatric conditions, is associated with worsened frequency or severity of migraine or headache disorders, this fact may be considered in the overall assessment of impairment. The criteria under 11.20 may be applied only if the impairment persists despite the individual adhering to a prescribed and supervised course of treatments that are consistent with the current standard of medical and surgical care, as supported by submitted documentation.

11.20 ***Migraine, trigeminal autonomic cephalalgias, cranial neuralgias, or other headache disorders - recurrent, severe symptoms, documented by detailed description of a typical attack or attack pattern, including associated phenomena, with symptoms occurring at least ten days per month in spite of at least 6 consecutive months of prescribed and medically supervised appropriate treatment of the headache disorders and any co-morbid disorders also contributing to impairment***. During symptomatic attacks there are pervasive and significant effects involving two or more of the following domains: interference with activity during the day; alteration of awareness or perception; impaired functioning in social environments; difficulty maintaining sustained concentration, persistence, or pace when completing tasks; inability to tolerate increased mental demands, time constraints, or routine movements; or extreme sensitivity to environmental changes or sensory exposures."

Exhibit I:
AHDA letter 2



Alliance for Headache Disorders Advocacy

Alliance for Patient Access
American Academy of Neurology
American Headache Society
Clusterbusters
Headache Cooperative of New England
Headache Cooperative of the Pacific
Migraine Research Foundation
Miles for Migraine Races
National Headache Foundation
National Migraine Association
Ohio Headache Association
PFO Research Foundation

To: Acting Commissioner Carolyn Colvin
Social Security Administration

April 27, 2014

Dear Acting Commissioner Colvin:

I respectfully write to you on behalf of the Alliance for Headache Disorders Advocacy (AHDA), a 501(c)(6) non-profit organization representing 12 non-profit groups advocating for Americans with disabling headache disorders. I am the Founding, and Immediate Past, President of the AHDA.

On March 15, 2013, the AHDA submitted to SSA a draft Headache Disorders listing (appended below) to be considered for inclusion in the revised neurological disorders Blue Book listings during the current rule-making process. We were very disappointed to learn that this listing was not further considered for inclusion in the Blue Book and we urgently appeal to you at this time to reconsider and reverse this decision.

Three key arguments support the inclusion of a Headache Disorders listing in the SSA Blue Book Listing of Impairments.

1) First, the sheer magnitude of the disability burdens that accrue from headache disorders makes the absence of a Blue Book listing for these disorders grossly anomalous.

- Migraine alone accounts for more than half of global neurological disability (YLDs) (Murray et al. *Lancet* 2012;380:2197, Vos et al. *Lancet* 2012;380:2163), and is the 7th leading cause of all global disability (Steiner et al. *Headache* 2013;53:227).

- Migraine accounts for more than twice the United States YLDs accruing from multiple sclerosis, epilepsy, and Parkinson's *combined*, yet each of these disorders is represented by a listing of impairment in the Blue Book, whereas migraine is absent.

- Total US lost work productivity due to all headache disorders was more than 4 times greater due to presenteeism ($16.4B/year), than due to absenteeism ($3.6B/year) (Stewart et al. *JAMA* 2003;290:2443).

- A Norwegian population-based study found that individuals with headaches occurring 15 or more days per month take an average of 14 lost work days due to absenteeism annually, whereas 20% of such individuals take at least 8 weeks of sick leave per year (Fiane et al. *Cephalalgia* 2006;26:960).

- On average, US workers with 15 or more days with migraine headache per month lose 5.7 hours of work productivity per week, comprising an average loss of approximately 14% of total productivity for each of these workers. 18% of such workers were on medical leave from work (Stewart et al. *JOEM* 2010;52:8).

- Americans with migraine are less likely to be employed in correlation with the frequency of their days with headache (37% full-time employed if 15 or more headache days per month vs.

48% full-time employed if 3 or fewer headache days per month). People with frequent or severe headaches have an unemployment rate 2.5 to 4 times the regional average (Stang et al *J Gen Intern Med* 1998;13:296, Von Korff et al *Pain* 1992;50:133).

- Overall, approximately 10% of Americans with episodic migraine (i.e. 14 days or fewer days per month) and 20% of Americans with chronic migraine (i.e. 15 or more days per month) report being "occupationally disabled" (Manack et al. *Curr Pain Headache Rep* 2011;15:70). Accepting these estimates, and considering the relative prevalence of migraine forms across the approximately 200 million Americans between the ages of 18 and 65 years, perhaps 3 million Americans may be currently occupationally disabled by migraine, either alone or in combination with other co-morbid disabling conditions, such as psychiatric, pain, respiratory, or cardiovascular disorders.

Additionally, multiple other disabling headache disorders, such as chronic cluster headache, post-traumatic headache, trigeminal neuralgia, etc., certainly increase the prevalence of occupationally disabled Americans, perhaps by hundreds of thousands of individuals.

2) **The second major argument for inclusion of a headache disorders Blue Book listing is that evaluation and adjudication of disability claims for headache disorders under an "analogous" listing fails to provide equal protection of the laws under Section 1 of the 14th amendment of the United States Constitution.** That is, headache claimants are denied equal standing to other American disability claimants when their claims are assessed under Blue Book criteria for an "analogous" listing that is, in fact, insufficiently analogous.

In a letter that you wrote to Senator Max Baucus dated February 6, 2014 (appended below), you state:

"We are aware of how severe the symptoms of chronic migraine and cluster headaches can be for some individuals. We generally evaluate chronic migraine and cluster headaches in adults under the most analogous listing - non-convulsive epilepsy - because both migraine and epilepsy are episodic and share some impairment similarities. Our adjudicators have received specific training and policy guidance on how to evaluate migraine and cluster headaches. This guidance explains that migraine and cluster headaches may result in associated phenomena such as alteration of awareness or consciousness, aura, photophobia, and pain."

You state that the most analogous Blue Book listing to headache disorders is 11.03:

11.03 Epilepsy - nonconvulsive epilepsy (petit mal, psychomotor, or focal), documented by detailed description of a typical seizure pattern including all associated phenomena, occurring more frequently than once weekly in spite of at least 3 months of prescribed treatment. With alteration of awareness or loss of consciousness and transient postictal manifestations of unconventional behavior or significant interference with activity during the day.[http://www.ssa.gov/disability/professionals/bluebook/11.00-Neurological-Adult.htm#11_03]

We thereby understand that for headache disorders claimants, SSA adjudicators have received specific training based on a non-publically disclosed SSA headache disorders "policy guidance" to take into consideration the episodic nature of these disorders and their associated phenomena *as they relate to meeting or medically equaling the 11.03 listing*. Unfortunately, 11.03 is a poorly analogous condition. Non-convulsive seizures may be associated with developmental delay and other manifestations and injuries not applicable to headache disorders, and headache disorders may have disabling symptomatic manifestations not reported for individuals experiencing non-convulsive seizures.

Moreover, an adjudication process based on analogy to listing 11.03 is totally opaque: nowhere has SSA published any further specifics or details of this headache disorders policy guidance or codified the full range of phenomena associated with headache disorders that adjudicators are instructed to consider in evaluating disability claims. There is no language within listing 11.03 to ensure that all germane and potentially disabling symptoms and signs of headache disorders would be considered in evaluation of meeting or medically equaling the 11.03 listing. For example, how do adjudicators handle claims of disability due to migraine where there is no headache symptom present at all (e.g. prolonged isolated aura, visual snow, abdominal migraine, cyclic vomiting, recurrent or prolonged vertigo, etc.)? There is no indication in the language in listing 11.03 which would clarify or ensure that a claimant with bona fide migraine who is significantly impaired by non-headache symptoms would be considered disabled in the absence of the symptom of headache. Are adjudicators even permitted to take such symptoms and signs into consideration in evaluating claims? In the absence of clear adjudication criteria published in the public domain (i.e. a Blue Book listing or Policy Interpretation Ruling), how can headache disorders claimants be expected to know which aspects of their complex medical histories will be considered as relevant or irrelevant to supporting their claims for disability? This uncertainty puts headache disorders claimants at a distinct and significant disadvantage in making their disability claims relative to other claimants experiencing a similar magnitude of disability for which a Blue Book listing is present.

3) **Finally, the absence of a headache disorders Blue Book listing, or other codified and published SSA impairment criteria, invalidates or diminishes the public perception of the legitimate impairments that individuals with severe headache disorders must bear.** This judgment, which carries the weight of a federal agency, further significantly stigmatizes these individuals, thereby compounding their suffering and disability.

We are aware that the last full revision of the neurological disorders Blue Book listings occurred in 1985, and we strongly hope that you take the current extremely rare opportunity to afford fairness and equity to the millions of Americans struggling with legitimate impairments from headache disorders.

Thank you very much for your consideration of our concerns.

Sincerely,

Robert E. Shapiro

Robert E. Shapiro, MD, PhD

Founding and Immediate Past President, Alliance for Headache Disorders Advocacy
Immediate Past President, Headache Cooperative of New England

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Proposed Draft Headache Disorders Listing for the SSA Listing of Impairments (Blue Book):

"H. *Headache Disorders, including migraine, trigeminal autonomic cephalalgias, cranial neuralgias, and related disorders*. The degree of impairment due to headache disorders will be determined according to the frequency, duration, severity, and sequelae of symptomatic attacks and their impacts on functional activities. Migraine and other primary headache disorders are not typically associated with clear or reliable diagnostic findings on physical examination, and no validated biomarkers, imaging abnormalities, or laboratory findings are typically diagnostic of the diseases. Whenever appropriate, attributed diagnoses should be consistent with the clinical diagnostic criteria of the current edition of the *International Classification of Headache Disorders* (ICHD). A detailed description of the individual's typical or idiosyncratic attack or attack pattern of headache disorder is required. Such descriptions may include, but may not be limited to, the frequency, duration, and presence or absence of (a) premonitory symptoms, (b) 'aura' symptoms of disturbances of vision, skin sensation, language, strength, coordination, or vestibular function, (c) location, severity, duration, and qualities of eye, ear, nose, mouth, face, jaw, head, neck, or shoulder pain, (d) amplified, distorted, or pain-inducing sensation to light, sound, touch, movement, smell, or taste, (e) autonomic disturbances including nausea, vomiting, abdominal pain, gastroparesis, diarrhea, constipation, increased lacrimation, ptosis, peri-orbital edema, pupillary abnormalities, rhinorrhea, sweating, or nasal/sinus symptoms, or (f) disturbances of cognition, affect, concentration, language, motivation, attention, agitation, or tolerance of stressful or social environments. To establish a medically determinable impairment due to a headache disorder, an individual must submit supportive documentation of the frequency of impairing symptoms of that disorder. Such documentation may include data from symptom diaries, clinical or functional questionnaire records, medical records, reporting health care provider attestations and documentation, and other sources of ancillary information such as the frequency and nature of evaluations and treatments in emergency departments or other clinical settings. Evaluation of the severity and disability burden of headache disorders may also include, but would not require, consideration of data from validated survey instruments, such as, but not limited to, the Headache Impact Test-6 (HIT-6), the Migraine Disability Assessment Test (MIDAS), the Henry Ford Headache Disability Inventory (HDI), or the Migraine-Specific Quality of Life Questionnaire (MSQ). Where documentation shows that the frequency of use of analgesic medications may have worsened the frequency or severity of migraine or other headache disorder, as in medication adaptation headache or analgesic-overuse headache, this fact should not be considered adversely in the overall assessment of impairment. When a history of physical or other traumatic or abusive experiences, or of co-morbid medical conditions, including psychiatric conditions, is associated with worsened frequency or severity of migraine or headache disorders, this fact may be considered in the overall assessment of impairment. The criteria under 11.20 may be applied only if the impairment persists despite the individual adhering to a prescribed and supervised course of treatments that are consistent with the current standard of medical and surgical care, as supported by submitted documentation.

11.20 ***Migraine, trigeminal autonomic cephalalgias, cranial neuralgias, or other headache disorders - recurrent, severe symptoms, documented by detailed description of a typical attack or attack pattern, including associated phenomena, with symptoms occurring at least ten days per month in spite of at least 6 consecutive months of prescribed and medically supervised appropriate treatment of the headache disorders and any co-morbid disorders also contributing to impairment***. During symptomatic attacks there are pervasive and significant effects involving two or more of the following domains: interference with activity during the day; alteration of awareness or perception; impaired functioning in social environments; difficulty maintaining sustained concentration, persistence, or pace when completing tasks; inability to tolerate increased mental demands, time constraints, or routine movements; or extreme sensitivity to environmental changes or sensory exposures."

Exhibit J:
POMS DI 24505.015(B)(7)(b) (05/13/2016)

Program Operations Manual System (POMS)

Effective Dates: 05/13/2016 - Present

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TN 3 (04-11)

DI 24505.015 Finding Disability Based on the Listing of Impairments

Citations:

20 CFR 404.1525 , 404.1526 , 404.1528 , 404.1529 , 416.925 , 416.926 , 416.928 , and 416.929

A. Listing of Impairments

1. What is the purpose of the Listing of Impairments?

The Listing of Impairments is in DI 34000.000. It describes impairments for each of the major body systems that we consider to be severe enough to prevent a claimant from doing any gainful activity, regardless of his or her age, education, or work experience.

2. How is the Listing of Impairments organized? There are two parts in the Listing of Impairments

a. Part A

Contains criteria that apply to claimants age 18 and over. We may also use Part A for claimants who are under age 18 if the disease processes have a similar effect on adults and children.

b. Part B

Contains criteria that apply only to claimants who are under age 18. We never use the listings in Part B to evaluate claimants who are age 18 or older. In evaluating disability for a claimant under age 18, we use Part B

first. If the criteria in Part B do not apply, we may use the criteria in Part A when those criteria give appropriate consideration to the effects of the impairment(s) in children. To the extent possible, we number the provisions in Part B to maintain a relationship with their counterparts in Part A.

3. How do we use the listings?

a. Each body system section in Parts A and B of the Listing of Impairments is in two parts: an introduction, followed by the specific listings.

b. The introduction to each body system contains information relevant to the use of the listings in that body system; e.g., examples of common impairments in the body system and definitions used in the listings for that body system. We may also include specific criteria for establishing a diagnosis, confirming the existence of an impairment(s), or establishing that an impairment(s) satisfies the criteria of a particular listing in the body system. Even if we do not include specific criteria for establishing a diagnosis or confirming the existence of an impairment(s), the claimant must still show that he or she has a severe medically determinable impairment(s) as defined in DI 24505.001.

c. The specific listings follow the introduction in each body system, after the heading, "Category of Impairments." Within each listing, we specify the objective medical and other findings needed to satisfy the criteria of that listing. We will find that an impairment(s) meets the requirements of a listing when it satisfies all of the criteria of that listing, including any relevant criteria in the introduction, and meets the duration requirement.

d. Most of the listed impairments are permanent or expected to result in death. For some listings, we state a specific period of time for which an impairment(s) will meet the listing. For all others, the evidence must show that an impairment(s) has lasted or can be expected to last for a continuous period of at least 12 months.

e. If an impairment(s) does not meet the criteria of a listing, it can medically equal the criteria of a listing. We explain our rules for medical equivalence in DI 24505.015B. in this section. We use the listings only to find that the claimant is disabled or still disabled. If the claimant's impairment(s) does not meet or medically equal the criteria of a listing, we may find that he or she is disabled or still disabled at a later step in the sequential evaluation process.

4. Can an impairment(s) meet a listing based only on a diagnosis?

No. An impairment(s) cannot meet the criteria of a listing based only on a diagnosis. To meet the requirements of a listing, the claimant must have a medically determinable impairment(s) that satisfies all of the criteria in the listing.

5. How do we consider symptoms when we determine whether an impairment(s) meets a listing?

Some listed impairments include symptoms, such as pain, as criteria. DI 24515.061D.2. and DI 24515.061D.3.

explain how we consider symptoms when they are included as criteria in a listing.

B. Medical equivalence

1. What is medical equivalence?

An impairment(s) is medically equivalent to a listed impairment in the Listing of Impairments if it is at least equal in severity and duration to the criteria of any listed impairment.

2. How do we determine medical equivalence?

We can determine medical equivalence in the following three ways:

a. If the claimant has an impairment that is described in the Listing of Impairments, but:
   - The claimant's impairment does not exhibit one or more of the findings specified in the particular listing; or
   - The claimant's impairment does exhibit all of the findings, but one or more of the findings is not as severe as specified in the particular listing; then
   - We determine the claimant's impairment is medically equivalent to that listing if they have other findings related to their impairment that are at least of equal medical significance to the required criteria.

b. If the claimant has an impairment that is not described in the Listing of Impairments, we will compare their findings with those for closely analogous listed impairments. If the findings related to the claimant's impairment are at least of equal medical significance to those of a listed impairment, we determine their impairment is medically equivalent to the most closely analogous listing.

c. If the claimant has a combination of impairments, none of which meets a listing, we will compare their findings with those for closely analogous listed impairments. If the findings related to the claimant's impairments are at least of equal medical significance to those of a listed impairment, we determine the combination of impairments is medically equivalent to the most closely analogous listing.

NOTE: DI 24515.061D.3. explains how we consider symptoms, such as pain, when we make findings about medical equivalence.

3. What evidence do we consider when we determine if an impairment(s) medically equals a listing?

When we determine if an impairment(s) medically equals a listing, we consider all evidence in the claimant's case record about their impairment(s) and its effects on them that are relevant to this finding. We do not consider the vocational factors of age, education, and work experience. We also consider the opinion given by one or more medical or psychological consultants designated by the Commissioner.

4. Who is a designated medical or psychological consultant?

A medical or psychological consultant designated by the Commissioner includes any medical or psychological consultant employed or engaged to make medical judgments by the Social Security Administration, the Railroad Retirement Board, or a State agency authorized to make disability determinations. For claims adjudicated under the administrative review process, a designated consultant includes a medical or psychological expert. A medical consultant must be an acceptable medical source identified in DI 22505.003A. A psychological consultant used in cases where there is evidence of a mental impairment must be a qualified psychologist. See DI 24501.001B.3. — DI 24501.001B.4. for limitations on what medical consultants who are not physicians can evaluate and the qualifications we consider necessary for a psychologist to be a consultant.

5. Who is responsible for determining medical equivalence?

In cases where the State agency or other designee of the Commissioner makes the initial or reconsideration disability determination, a State agency medical or psychological consultant or other designee of the Commissioner has the overall responsibility for determining medical equivalence (see DI 24501.001B.2). For cases in the disability hearing process or otherwise decided by a hearing officer, the responsibility for determining medical equivalence rests with the disability hearing officer. For cases at the Administrative Law Judge or Appeals Council level, the responsibility for deciding medical equivalence rests with the Administrative Law Judge or Appeals Council.

6. What are the rationale requirements for each of the three ways to find medical equivalence?

If an impairment(s) medically equals the severity of a listed impairment and meets the duration requirement, find that the claimant is disabled or still disabled. For all medical equivalence determinations, prepare a rationale according to the guidelines in this section. The rationale must reflect consideration of the pertinent evidence of record and reconcile or resolve significant inconsistencies. The adjudicator must include the items listed below in the rationale.

NOTE: When substituting a finding or symptom from a listing, the adjudicator may only substitute symptoms for other symptoms and findings for other findings. Never substitute a symptom for a finding.

a. If a claimant has a listed impairment, there are two possible scenarios.

   First scenario: The claimant's impairment does not exhibit one or more of the findings specified in the listing:

   - Discuss the claimant's impairment, medical findings, and non-medical findings.
   - Discuss the findings required to meet the listed impairment.
   - Discuss the required finding(s) that are missing in the findings of the claimant's impairment.
   - Discuss the finding(s) of the claimant's impairment that is at least of equal medical significance to the required findings.

- Explain why we can substitute those findings to medically equal the listed impairment.
- Cite the listing for the medical equivalence determination.

b. Second scenario: The claimant's impairment exhibits all of the required findings, but one or more of the findings is not as severe as specified in the listing:

- Discuss the claimant's impairment, medical findings, and non-medical findings.
- Discuss the findings required to meet the listing.
- Identify the finding or findings related to the claimant's impairment that is not as severe as specified in the listing.
- Discuss the finding(s) of the claimant's impairment that is at least of equal medical significance to the required findings.
- Explain why we can substitute those findings to medically equal the listed impairment.
- Cite the listing for the medical equivalence determination.

c. For an unlisted impairment:

- Discuss the claimant's impairment(s), medical findings, and non-medical findings.
- Discuss the listing we are considering to use as the most closely analogous listing.
- Compare the findings of the claimant's impairment to the findings for the most closely analogous listing.
- Explain why the findings of the claimant's impairment are at least of equal medical significance to the findings of the most closely analogous listing.
- Cite the most closely analogous listing used to determine medical equivalence.

d. For a combination of impairments:

- Discuss the claimant's impairments, medical findings, and non-medical findings.
- Discuss the listing we are considering to use as the most closely analogous listing.
- Compare the findings of the claimant's impairments to the findings for the most closely analogous listing.
- Explain why the findings of the claimant's impairments are at least of equal medical significance to the findings of the most closely analogous listing.
- Cite the most closely analogous listing used to determine medical equivalence.

7. Examples of rationales for medical equivalence determinations

These rationales are examples only.

a. Listed impairment

First Example:

A claimant alleges difficulty walking, chronic pain, and limitation of motion in the left knee. X-ray findings reveal degenerative arthritis without deformity of either knee. Treatment records show the claimant is morbidly obese with a BMI of 56.5 (5'6"; 350 pounds), has chronic joint pain, limitation of motion, and great difficulty walking. He walks very slowly and can walk only short distances before he has to stop and rest. He becomes short of breath on exertion, especially walking up steps.

On the SSA-3367 (Disability Report), the field office claims representative (CR) included observations of the claimant's gait. The claimant:

- used a walker to move from the waiting room to the interview area;
- leaned on the walker, took only a few steps at a time, and then had to stop and start over again; and
- appeared to be in great pain while walking.

In addition, a Department of Veterans Affairs social worker (SW) made similar observations in the treatment records.

The claimant's impairment is missing findings (gross anatomical deformity and stiffness) required to meet listing 1.02A. Obesity, which contributes to the claimant's shortness of breath and inability to walk effectively, is at least of equal medical significance to the required findings in listing 1.02A. Therefore, the claimant's impairment medically equals listing 1.02A.

Second Example:

A claimant has a history of a left ankle fracture. Post-fracture he developed chronic pain in his right knee. Current medical records show chronic pain on weight-bearing, stiffness, limitation of motion of the left ankle and right knee, and significant difficult walking. His physical therapist prescribed bilateral canes or a walker for ambulation. X-rays show arthritis of the left ankle and degenerative joint disease of the right knee. Listing 1.02A requires involvement of one major weight-bearing peripheral joint. Findings of the claimant's impairment include all required findings of 1.02A, except gross anatomical deformity. The claimant's impairment involves two major weight-bearing joints. This medical finding is at least of equal medical significance to the missing finding, gross anatomical deformity. Therefore, the claimant's impairment medically equals listing 1.02A.

b. Unlisted impairment

First example:

A claimant has Prader-Willi Syndrome (PWS) with cognitive disabilities, decreased muscle tone, short stature, emotional liability, and an insatiable appetite. He is 64" tall and weighs 300 pounds. IQ testing is not available. Genetic clinic records confirm chromosome 15 findings consistent with PWS. The claimant was home-schooled due to his extreme behavior problems, such as temper tantrums, perseveration, and compulsive-like behaviors. When he attended school he would take food from other students. He does not get along with people and has very few social skills. To aid in restricting his food intake at home, his parents placed locks on all food cabinets, the refrigerator, and even garbage cans. Listing 12.02, Organic Mental Disorders, is the most closely analogous listed impairment. The claimant has behavioral abnormalities associated with his genetic condition. Laboratory tests confirm his diagnosis. He is completely dependent on his parents in all areas of functioning. These findings

are at least of equal medical significance to listing 12.02. Therefore, the claimant's impairment medically equals listing 12.02A.6.B1. and B.2.

Second Example:

A claimant has chronic migraine headaches for which she sees her treating doctor on a regular basis. Her symptoms include aura, alteration of awareness, and intense headache with throbbing and severe pain. She has nausea and photophobia and must lie down in a dark and quiet room for relief. Her headaches last anywhere from 4 to 72 hours and occur at least 2 times or more weekly. Due to all of her symptoms, she has difficulty performing her ADLs. The claimant takes medication as her doctor prescribes. The findings of the claimant's impairment are very similar to those of 11.03, Epilepsy, non- convulsive. Therefore, 11.03 is the most closely analogous listed impairment. Her findings are at least of equal medical significance as those of the most closely analogous listed impairment. Therefore, the claimant's impairment medically equals listing 11.03.

c. Combination of impairments

First Example:

An adult claimant has chronic venous insufficiency, type 1 diabetes mellitus (DM), and peripheral neuropathy. Medical evidence reveals chronic edema in both legs, stasis dermatitis, and persistent ulcerations on the right lower leg that have not healed despite treatment for more than 6 months. He has numbness, burning sensations, and sometimes weakness in both legs, and walks with a wide-based antalgic gait (a self-protective limp due to pain). He also has difficulty rising from a chair. We determine that the evidence does not document that the claimant's chronic venous insufficiency satisfies the requirements in listing 4.11(A or B), Chronic venous insufficiency. The evidence does not document extensive brawny edema that we require in listing 4.11A or superficial varicosities (in addition to stasis dermatitis and persistent ulceration) that we require in listing 4.11B. We determine, however, that when we consider the claimant's combined impairments that listing 4.11B is the most closely analogous listed impairment. The claimant's combined findings of both chronic venous insufficiency and DM are at least of equal medical significance. Therefore, the combination of the claimant's impairments medically equals listing 4.11B.

Second Example:

A claimant was involved in a car accident. He was ejected from the car and then trapped under the exhaust system, which resulted in second and third degree burns to his right torso and the left side of his face. The burns were very severe and he spent three months in a burn center where he had multiple surgeries. Eight months after the accident, the claimant attended a consultative exam (CE). He has limitation of motion of both right extremities due to contractures and pain. However, this limitation does not negatively affect his overall physical functioning. The claimant's primary alleged disability is related to his facial appearance. At the CE, the physical description showed a terribly deformed face and neck on the left side. His left external ear is absent. He has deformity, contractures, scarring, and abnormalities of the entire left side of his face. His appearance is very grotesque and he is very self-conscious. Even at home he wears a bandage to cover his face. He is depressed, has a flat affect, and does not smile. He has severe anxiety about being around people. He refuses to go out unless it is absolutely necessary. He has a sense of panic about driving and being around people, so he avoids these situations when possible. His wife always accompanies him. His mental diagnoses are psychosocial trauma and stressors due to

his facial disfigurement; depression and anxiety disorder, both untreated.

The claimant's impairment does not meet listing 8.08 (specifically the introductory test in 8.08 C and F) because his musculoskeletal residuals from the burns do not seriously limit use of more than one extremity. Per the introductory test in 8.08D.4, we evaluate facial deformities under the 12.00 listings. DDS Psychological Consultant states that claimant does not technically meet listing 12.06, anxiety disorder. However, the most closely analogous listed impairment is listing 12.06. Combining the findings of the burn residuals and findings related to his anxiety, the total findings are at least of equal medical significance to the findings in either listing 8.08 or 12.06. Therefore, we determine the claimant's impairments medically equal listing 12.06A.2. B.1. and B.2.

C. References

- DI 22001.001D.3, Impairment(s) Meets or Medically Equals a Listing
- DI 24501.020, Symptoms, Signs, and Laboratory Findings
- DI 24515.061, How We Evaluate Symptoms, Including Pain
- DI 25220.010, Meets or Medically Equals
- DI 34000.000, Listing of Impairments – Current

Exhibit K:
Letter from SSA Acting Commissioner Carolyn W. Colvin (2/6/14)

SOCIAL SECURITY

The Commissioner

February 06, 2014

The Honorable Max Baucus
Chairman, Committee on Finance
United States Senate
Washington, DC 20510

Dear Mr. Chairman:

Thank you for your April 16, 2013 letter on behalf of your constituent, John Bebee, concerning raising awareness of severe headache disorders. I apologize for the delayed response. As you noted, advocates from the Alliance for Headache Disorders Advocacy have provided us with draft language on severe headache disorders, which they would like us to include in our Listing of Impairments. We are giving the proposed language full and careful consideration.

We are aware how severe the symptoms of chronic migraine and cluster headaches can be for some individuals. We generally evaluate chronic migraine and cluster headaches in adults under the most analogous listing–non-convulsive epilepsy–because both migraine and epilepsy are episodic and share some impairment similarities. Our adjudicators have received specific training and policy guidance on how to evaluate migraine and cluster headaches. This guidance explains that migraine and cluster headaches may result in associated phenomena such as alteration of awareness or consciousness, aura, photophobia, and pain.

We are drafting and plan to publish soon a Notice of Proposed Rulemaking that would revise our criteria for evaluating neurological disorders in adults and children. When published, we will notify all interested stakeholders through the formal rulemaking process so they may provide public comments for us to consider.

I hope that this information is helpful. If I may be of further assistance, please contact me, or your staff may contact Scott Frey, our Deputy Commissioner for Legislation and Congressional Affairs, at (202) 358-6030.

Sincerely,

Carolyn W. Colvin

Carolyn W. Colvin
Acting Commissioner